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Policy, Identity and Practice:
A Study of how Policy Decisions Regarding the Welfare of Children with
Disabilities are Formulated within the Portuguese Welfare State

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Declaration

I declare that this thesis is of my own composition, based on my own work, with acknowledgement of other sources, and has not been submitted for any other degree or professional qualification.

Sandra Sibel Cabrita Gulyurtlu

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Abstract

This thesis seeks to explore how key decision-makers within the Portuguese civil service formulate decisions regarding policies orientated at children with disabilities. It breaks the issue down by focusing on three main perspectives - the decision-maker, the policy framework and children with disabilities. The decision-maker was analysed in the context her/his professional identity. By combining social identity theory (self-categorisation) and identity theory (role-identification) and interview data, this thesis found that the basis for decision-making was the way in which the term 'children with disabilities' was identified and conceptualised by the decision-maker, as well as the associated approaches, rules and guidelines at both the national and international level. It found a variable balance of influences between the concepts of parenting and families, the norms of the Portuguese welfare system and the emergent international thinking regarding children with disabilities. Through the use of a multi-method approach which incorporated interviews, vignettes and documentary analysis this thesis captured the approaches of each decision-maker. This thesis found that children with disabilities were predominantly viewed as dependants. The familialist structure of the Portuguese welfare state introduces the notion of a 'disabled family', whereby the family carries the responsibility of addressing the challenges associated with children's disability and state support is directed at the family. In addition, this thesis found that 'normalisation' was the predominant approach to disability, regardless of intended approach of each decision-maker. This study concluded that a combination of rehabilitative and integrative policy impulses in a context of limited and incomplete information and guidelines from international organisations have influenced this approach.

Abbreviations

APD	<i>Associação Portuguesa de Deficientes</i> (Portuguese Association of People with Disabilities)
CERCI	<i>Centro Especial de Reabilitação de Crianças Inadaptadas</i> (Special Rehabilitation Centre for Maladapted Children)
CNPCJR	<i>Comissão Nacional de Protecção de Crianças e Jovens em Risco</i> (National Commission for the Protection of Children and Young People at Risk)
DGIDC	<i>Direcção Geral de Inovação e Desenvolvimento Curricular</i> (Directorate General for Innovation and Curricular Development)
DGSS	<i>Direcção Geral da Segurança Social</i> (Directorate General of Social Security)
DREL	<i>Direcção Regional Da Educação De Lisboa</i> (Regional Directorate for Education in Lisbon)
DSA	Down's Syndrome Association
EYPD	European Year of the People with Disabilities
FENACERCI	<i>Federação Nacional das Cooperativas de Solidariedade Social</i> (National Federation of Cooperatives of Social Security)
GOP	<i>Grandes Opções do Plano</i> (Grand Options of the Plan)
ICF	International Classification of Functioning
ISS	<i>Instituto da Segurança Social</i> (Institute for Social Security)
IT	Identity Theory
IPSS	<i>Instituição Particular de Solidariedade Social</i> (Private Institutions of Social Security)
NAS	National Autistic Society
OECD	Organisation for Economic Co-operation and Development
PG	<i>Programa do Governo</i> (Program of the Government)

PNAI	<i>Plano Nacional de Acção para a Inclusão</i> (National Plan for Action Inclusion)
PNE	<i>Plano Nacional do Emprego</i> (National Plan for Employment)
PNPA	<i>Plano Nacional de Promoção da Acessibilidade</i>
SIT	Social Identity Theory
SNRIPD	<i>Secretariado Nacional para a Reabilitação e Integração das Pessoas com Deficiência</i> (National Secretariat for the Rehabilitation and Integration of People with Disabilities)
UNCRC	United Nations Convention for the Rights of the Child
UNCRPD	United Nations Convention for the Rights of Persons with Disabilities
UNESCO	United Nations Educational, Scientific and Cultural Organisation
UNICEF	United Nations Children's Fund
WHO	World Health Organisation

1. Introduction

Goodwin (1988) argued that the welfare state, rather than controlling or manipulating the market, perhaps corrects and remedies undesired and unplanned outcomes within the economy. Esping-Andersen (1999) too has characterised the welfare state as:

Not just a mechanism that intervenes in, and possibly corrects, the structure of inequality; it is in its own right, a system of stratification. (Esping-Andersen, 1999: 23)

Thus the welfare state can be viewed as a system that corrects the inequalities present within society, whilst at the same time structuring and ordering social relations. Usually, the stratification which Esping-Anderson speaks of is achieved through a network of public and/or social policies targeting specific areas that need ‘correcting’. Goodwin (1988) supports this statement, although he emphasises that the welfare system generally limits inequality rather than eliminating it altogether. Each welfare state has its own structure and, therefore, its own unique regime that results from the conditions encountered in that specific state.

This study aimed to explore the unique nature of the Portuguese welfare state; a southern European welfare regime with a characteristic familialist structure, which is currently under-represented in the welfare state literature. The Portuguese welfare regime has a low level of state penetration and a high level of reliance on the domestic sphere for welfare provision (see Sousa Santos 1994; Ferrera, 1996), relying on a complex mix of private-public partnerships for social provision. However, as studies suggest (see OECD, 2003) this welfare structure has certain limitations that mainly lie within the structure and function of the civil service. There are many weaknesses in the Portuguese civil service in terms of both cross-departmental and inter-ministerial communication as well as the coordination and qualifications of its employees. This study wished to explore how successful this particular welfare structure is in correcting the inequalities present in Portuguese society and in giving order to its social relations. Its focus will be on the civil service and, more specifically, the civil servants and decision-makers within it, as well as the link which exist between the civil service and the private/voluntary sector. This study

views social policy as a decision-making process. Consequently, these are the actors who take part in formulating policy decisions (see Hill and Bramley, 1986).

Children with disabilities provided an ideal case study through which to explore policy decision-making in Portugal. Being a familialist welfare regime means that this country centres its welfare structure around the family. Children with disabilities are surrounded by a series of complex social networks in addition to the family (see Hill and Tisdall, 1997), resulting in a somewhat detached relationship with the welfare state. The familialist regime suggests that the family acts a buffer between state and child. Children with disabilities, and people with disabilities in general, need specialist support that must be addressed on various social, structural and political levels, as disability is encountered at a variety of levels, from impairment to discrimination, (see Sim *et al.* 1998). For this reason, certain conditions encountered by children with disabilities have to be addressed by the state directly and not just through means of policies aimed at the family. This thesis aims to explore this complex policy structure which exists surrounding children with disabilities, the family and the state. It will attempt to explore whether children with disabilities and their needs are being overlooked due to this complex welfare structure.

1.1 Research Questions

In order to explore policy-making in the Portuguese welfare state regarding children with disabilities, this study focused on the conceptualisation of children with disabilities by key policy decision-makers in the Portuguese civil service. This was done by examining the schematic approaches these decision-makers have regarding their professional conduct. Schemas are ‘mental frameworks, centring on a specific theme, that help us to organize social information’ (Baron *et al.*, 2006: 42). This particular branch of social psychology has a cognitive element to it in which the human mind can be seen as analogous with a computer hard drive, in possessing various methods of processing information. Schemas have been noted to be powerful mental information processing tools (Baron *et al.*, 2006). In being a victim of social influences, the information we collect from our surroundings and daily lives, is vast and complex. In order to avoid an ‘information overload’ (Baron *et al.*, 2006)

schemas are predetermined mental structures that detect, store and later on retrieve relevant information. The more consistent the information we encounter the stronger the schema becomes, to the point that we may even disregard information that contradicts our schema. This can be applied to the professional setting, studies such as those by Carroll (1993) have shown the longer the professional experience one has, the more precise and set responses one has to particular areas related to ones work. This is the result of practice. This study seeks to tap into the professional schemas of Portuguese civil servants regarding policies orientated at children with disabilities.

This study divided its main research question into three areas:

- What is the policy structure in which these professionals operate?
- What is the professional identity of the decision-makers and how does it impact on their decision-making?
- How are children with disabilities conceptualised in the policy decision-making arena?

This study interviewed eight top-ranking and mid-level civil servants working in areas related to children with disabilities. These informants were mainly found in the Ministries of Social Security and Education. In addition, because there is a heavy reliance on the private/voluntary sector for social provisions through a mixture of private-public partnerships, two prominent members of the private/voluntary sector were interviewed as well. In order to explore the professional conduct of these decision-makers, this thesis has adopted identity as the main approach to research this area. Sparks (2000) has noted the varying ‘selves’ we have in his account of the ‘utility of self-identity’. He claims we are a product of the society we live in, whereby our social influences construct who we are as individuals. This thesis aims to explore the decision-makers’ identity and how that influences the process through which they formulate decisions.

1.2 Research Methods

In order to explore these questions, this study chose a triangulated approach incorporating three complimentary research methods:

- Vignettes
- Semi-Structured Interviews
- Documentary Analysis

It was felt that these methods together would help in constructing a comprehensive study of decision-making in the Portuguese civil service regarding policies aimed at children with disabilities. The vignette technique was adopted in order to explore decision-making in action. This particular technique allows one to explore decision-making through the use of hypothetical or real-life scenarios. It is also a good ice-breaker for interviews (see Barter and Renold, 1999). Within this study, each of the civil servants were presented with a real-life story about a child with disabilities and his mother, and the difficulties they were encountering as a result of the child's disability. Following this story, the interviewees were asked to provide any advice they had on what this family could do to improve their current situation. The aim of this exercise was to view how these interviewees would put their policies into action, and if their responses to the vignette match those they gave in the interviews. Hence, it would allow us to see if the interviewees were consistent with the policy responses they advocated in the two parts of the interview.

The vignettes were followed by semi-structured interviews. Interviews were adopted in order to explore the informants' conscious approaches to policy decision-making regarding children with disabilities. The interviews followed a tree and branch structure (see Rubin and Rubin, 1995), where there were seven base questions, and all other questions followed on from these core questions. The questions were centred around different factors that would be considered when making a policy decision, such as policy plans and approaches, resource allocation and prioritisation associated with policies regarding children with disabilities. In addition, this thesis

also analysed written policies and guidelines identified in the interviews. This was done in order to construct the policy structure surrounding each of the informants.

1.3 Data Analysis

This study began by analysing written policies and guidelines pertaining to children with disabilities identified by the interviewees. These written policies and guidelines fell into three groups: international guidelines, governmental policy plans and national legislation. These documents were analysed in order to explore the policy structure in which these key decision-makers worked and the guidelines they used to formulate decisions.

This thesis adopted and amalgamated two theories of identity to produce a comprehensive approach with which to analyse the decision-makers. These theories are Identity Theory (IT) and Social Identity Theory (SIT). According to Hogg *et al.* (1995), IT focuses on how different roles or set social structures are identified and taken on by the individual. Consequently, identity is formed through role-identification (see Stryker and Burke 2000; Stryker and Serpe, 1994 *inter alia*). In contrast, SIT focuses on how individuals view themselves and how they associate themselves with a particular category and/or group. Identity is formed through a process of self-categorisation, e.g. I am a mother, a fireman, and so forth. Although Hogg *et al.* (1995) distinguish these two theories as being different and advocate SIT as a superior theoretical approach, as will be discussed in subsequent chapters these two theories can be combined to build a comprehensive approach to identity. These theories not only explore how individuals categorise themselves, but also what roles those (at times contradictory) categories entail.

In addition, this thesis explored how children with disabilities were conceptualised by the interviewees and within the context of the policy process. By understanding how children with disabilities are conceptualised and defined, one can understand at whom policies are directed and in what context (see Fulcher, 1989 and Bolderson and Mabbett, 1991). This analysis sought to understand the approach to children with disabilities in Portuguese policy. Children with disabilities are a social group that

suffers from many inequalities within society (see Marchant, 2001). By examining these difficulties encountered by children with disabilities and exploring the policy structure and provisions supporting children with disabilities, it allows one to view the extent to which the welfare state corrects inequalities and brings social order. When exploring the term ‘children with disabilities,’ this project divided this category into its two constituent components; *children* and *people with disabilities*.

The term ‘disability’ in the disability studies literature is usually associated with Mike Oliver (1996) and his distinction between the individual model and the social model. The individual or medical model views impairment as the cause of disability, and places the responsibility for supporting and caring for this disability on the individual. The social model, on the other hand, addresses the disabling (social) barriers which exist within society and puts pressure on society to change. However, as will be discussed below, the construction of disability is far more complex than this simple distinction. Disability and disablement can happen at various levels: at the level of the family, social services, even the state as well as the individual level. Consequently, there has been much debate about whether impairment should be included in the definition of disability and thus brought into the social model (see Crow, 1996). According to this logic, disability is not exclusively a social issue (see Low 2006). Nor, however, is it exclusively a medical issue. It is a culmination of different factors and circumstances that are included within these two models, ranging from impairment to lack of services or service planning (see Sim *et al.*, 1998).

Stalker *et al.* (1999) have highlighted what one says and, to a certain extent, what one consciously believes does not always match with what one does. Stalker *et al.*’s study found that although social workers said that they adopted the social model, their approach to policy was in fact slightly different to what this model advocates. It is clear from other literature (see Allan 2006, and Grovnik, 2007) that disability and the key concepts surrounding it are not clear and consistent in definition. All these issues have been explored in this thesis, and were used to analyse the data collected.

The term ‘children’ is also a highly complex concept. Children are usually seen as separate from the adult world and, to a certain extent, are unable to participate fully as individuals in ‘adult politics’ (see Archard, 1993). As discussed above, Portugal has a familialist welfare structure, meaning that the state relies on the family for welfare provision. Hence, children are usually addressed through the medium of the family and they do not deal directly with the state. This study explored the different social layers and networks surrounding children and children with disabilities in the policy context, by exploring at whom policies regarding children with disabilities are directed (see Hill and Tisdall, 1997). In sum, it is argued that by exploring these areas this thesis will answer its main research question: how do key policy decision-makers formulate decisions regarding policies orientated at children with disabilities within Portugal?

1.4 Contribution to Knowledge

This thesis aims to contribute to the limited literature which exists on Portugal, especially within the welfare state literature. In addition, it seeks to add to the field of disability and childhood studies as well as the field of social policy, and hopes to contribute to developing and improving policy and services orientated at children with disabilities within the Portuguese welfare system.

1.5 Thesis Outline

This thesis is divided into nine chapters. Chapter 2 reviews the relevant literature from the fields of social policy and the Portuguese welfare state, disability studies and childhood studies and sets out the theoretical base to this study. In addition, it examines in more detail the two theories of identity which inform this study. It starts by exploring the Portuguese welfare structure in detail. Subsequently, this chapter outlines the approach this thesis takes to social policy which, as illustrated above, will be examined using a combination of IT and SIT. Finally, this chapter deconstructs the term ‘disability’ and ‘children,’ before amalgamating the two into a comprehensive approach to understanding identity and the conception of ‘children with disabilities’.

Chapter 3 maps out the methodology of this study. As previously highlighted, this thesis adopted a triangulated approach encompassing three research methods: vignettes, interviews and documentary analysis. This chapter highlights the main characteristics of these methods and how they were applied to this study.

Chapter 4, 5 and 6 look at the written policy structure surrounding children with disabilities in which the interviewees operate. Within the interviews, the respondents identified three main areas that influenced the way they did their jobs and took policy decisions: governmental manifestos and policy plans, international guidelines and national legislation. As a result, these three forms of policy document were divided into three chapters treating each of these in turn. Chapter 4 focuses on international guidelines and explores the international influences highlighted within the interviews. Chapter 5 analyses manifestos from the current government and the government which preceded it were analysed as were policy plans for the related period (2002-2005). This chapter highlights the provisions and policies mentioned within these documents regarding children with disabilities. Chapter 6 focuses on national legislation that was also examined in the context of social security and education. This section highlights the particular pieces of legislation that were mentioned within the interviews. These chapters have been divided into the two main policy areas that the interviewees fall into: social security and education, and subsequently explored within these contexts.

Chapter 7 focuses on the professional decision-maker. This chapter is divided into two main areas focussing in turn on the self and the other. When exploring the self, this chapter focuses on how the interviewees described themselves in a professional context. This area is sub-divided into two main subsections dealing with key concepts emerging from SIT and IT respectively: self-categorisation and role-identification. Self-categorisation explores the categories that the interviewees used to identify themselves, and role-identification explores the roles the interviewees identified with in order to construct their professional identities. When exploring the conceptualisation of others, i.e. children with disabilities, this chapter looks at how, and with whom, the interviewees identified within the policy-making context. These

sections explore how decision-makers categorise themselves and associate their roles with other entities in the civil service and the private sector, illustrating the policy network perceived by each interviewee.

Chapter 8 focuses on the conceptualisation of children with disabilities in the policy context. From the interview data, three themes emerged when conceptualising children with disabilities: children and impairment, children with disabilities and children as dependents. This chapter addresses each of these themes in turn. The section on children and impairment analyses the interview responses that viewed children with disabilities first and foremost as children who have an impairment or an additional characteristic. Children with disabilities, or rather their disabilities per se, were the predominant theme in this area. The section on children with disabilities analyses notions of disability that emerged from the interviews. The third section on 'children as dependents' explores the responses to notions of dependency associated with childhood and disability. In addition, this chapter also highlights the responses elicited by the vignette. Within this context two areas arose by which children with disabilities were identified and defined. The first area analyses how the interviewees identified with the child within the vignette. The second area explores the notion of the disabled family, where the family unit is perceived as a single entity. The 9th and final chapter is the concluding chapter.

2. Literature Review: Positioning the Study

2.1 Introduction

When attempting to position this thesis in the context of existing scholarship in this field, one needs to break down the question at hand. The focus of the study is on how policy decisions, regarding the welfare of children with disabilities are formulated within the Portuguese civil service. This chapter will start by exploring the structure of the Portuguese welfare regime and the Portuguese state more generally. Portugal has been identified as a Southern European Welfare State with a familialist structure. The following section will ask what this means and, furthermore, how this structure impacts on and directs policy. In other words, it aims to set out the policy setting in which policies for disabled children are made.

Having established the policy setting, there will then be an exploration of the approach to policy this thesis will take. Since the current project is concerned with decision-making and how individuals come to a decision, it chose to take a social-psychological approach to policy by adopting two identity-related theories within this field: identity theory and social identity theory. Hence, it explores how the individual relates to and identifies with the policies she/he works with and the people the policies are directed at.

Once the approach to policy has been established, the remainder of the chapter will look at the two main areas that are being explored: disability and children. The term ‘children with disabilities’ incorporates two different social groups or categories that have different identities and needs, namely ‘children’ and ‘people with disabilities’. As a result, this chapter plans to take the conceptualisation and construction of both these categories, and combine them to build all-encompassing analytical framework to analyse policy regarding children with disabilities, where both perspectives shall be applied.

2.2 The Portuguese Welfare State

Esping-Andersen's 'Three Worlds of Welfare Capitalism' (1990) was revolutionary in setting a precedent on how to classify and categorise Welfare States. By measuring variations in relations between state, market and family with social rights, de-commodification and welfare-state stratification, Esping-Andersen (1990) identified 3 main welfare regime clusters with varying levels of de-commodification and stratification: liberal, corporatist and social democratic. These clusters had the following characteristics:

- The liberal welfare model in general has low levels of de-commodification, and provisions are usually means-tested and modest.
- The corporatist welfare regime, modelled by the church, seeks to maintain the traditional view of the two-parent family household. The State intervenes where the family is unable to care for its members. This welfare regime endorses status segmentation, where social rights are distributed accordingly.
- The social-democratic model, typically characteristic of Scandinavian countries, incorporates both high levels of de-commodification and universal, yet pluralist, welfare measures. - (Esping-Andersen, 1990)

This welfare clustering was subject to much criticism, not only from the feminist perspective (see Lewis, 1992 and Orloff, 1996) but also from the "Southern" familialist perspective (see Leibfried, 1992; Ferrera, 1996 and Martin, 1997). The first criticism focussed on the fact that these denominations do not take into account the gender roles in the welfare context, as well as the differential demography and characteristics of the population. The second criticism, meanwhile, argued that Southern European welfare states differ from corporatist regimes and require their own welfare denomination.

Portugal has often been seen as a state on the semi-periphery; a moderately industrialised state, which is not completely dominated by the central European economies, but which has nevertheless reached a certain level of political centralisation and organisation (Ramalho Correia *et al.*, 1997). Portugal, being partially industrialised, is still far from achieving a sound economic and political structure. In terms of its welfare state, Portugal has been classified as having a

familialist welfare regime. Familialist welfare regimes are especially evident in Southern Europe and, as the name suggests, the family is at the vanguard of welfare provision. They are distinguished by:

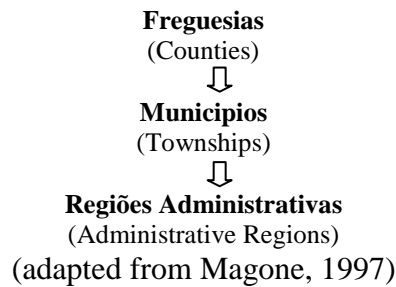
- High institutional fragmentation, where there is generous cover for some sectors of the population over others.
- The aim to have a universal national healthcare system.
- Low degree of state welfare penetration and a complex interplay between public and non-public actors and institutions.
- Persistence of clientalism in the access to state welfare provision. (Ferrera, 1996)

Esping-Andersen (1999), however, maintained that Mediterranean countries were corporatist regimes. To recapitulate, Esping-Andersen defined corporatism to be:

...typically shaped by the Church, and hence strongly committed to the preservation of traditional family-hood. Social insurance typically excludes non-working wives, and family benefits encourage motherhood. ... the principle of 'subsidiarity' serves to emphasise that the state will only interfere when the family's capacity to service its members is exhausted. (Esping-Andersen, 1990: 27)

He stated that the only slight variation between Southern European welfare states and other Continental European corporatist welfare states was that Southern European welfare states tended to place more welfare responsibility on the household. However, Ferrera (1996) and Martin (1997) have shown that the cleavages between these welfare regimes are far more complex and run far deeper than Esping-Andersen's analogy.

Firstly, Portugal is a relatively new welfare state, especially compared to its continental counterparts. It has been noted as still being in its early stages of decentralisation. The central government caters for the central administration and coordinates the regional commissions (Magone, 1997), whereas the local authorities are responsible for local administration. The following diagram outlines the structure of the local governments and their hierarchy. It begins with the smallest units of government and proceeds through to the largest units):



However, Magone argues that this system of decentralisation falls short of its function, since a large proportion of the civil service is included in the central administration and is distributed unevenly. There is a lack of coordination and communication between the different tiers of State administration, especially in terms of budgeting, (OECD, 2003). This provides support for Ferrera's argument that Southern States are fragmented in their social benefit system, and Portugal already can be seen as fitting into his framework on these grounds. Furthermore, according to Magone there is also a lack of educational proficiency, or a lack of qualifications on the part of civil servants, where responsibilities or 'competencies are not clearly defined' (OECD, 2003: 77).

Sousa Santos (1994:46) has argued that 'In Portugal a weak Welfare State co-exists with a strong welfare society.' Ramalho Correia *et al.* (1997) in their study on citizenship in Portugal refer to Sousa Santos's conceptual framework¹. They state he divides capitalist societies into four structural spaces, (domestic, production, citizenship, and world), which can be viewed below:

¹ Having read the original text by Sousa Santos, (found only in Portuguese), I chose to use Ramalho *et al.*'s translation as it depicts accurately Sousa Santos's work.

Structural spaces	Unity of social practices	Institutional form	Power mechanism	Type of right	Mode of rationality
Domestic spaces	Gender and generations	Family, marriage and kinship	Patriarchy	Domestic right	Maximisation of affection
Production spaces	Class	Company	Exploitation	Production right	Maximisation of profit
Citizenship spaces	Individual	State	Domination	Territorial right	Maximisation of loyalty
World spaces	Nation	Contracts, agreements and international organisations	Unequal inter-change	Systematic right	Maximisation of effectiveness

- Domestic space – social relations among family members
 - Production space – work relations at company level
 - Citizenship space – social relations at public level; between the citizens and the state
 - World Space – International relations; economic and relations between nation states
- (adapted from Ramalho Correia *et al.*, 1997:222; Sousa Santos, 1994:112)

The production space needs domestic and citizenship spaces to run smoothly in order to operate effectively. By giving social order, and also by keeping the worker ‘happy,’ provides the grounds for economic activity to take place effectively, and the labour force to work at optimum level. As stated by Lavalette,

Social policies and spending on social services and welfare provision are only part of any State's activities which are geared to enabling capitalism to exist or expand. - (Lavalette, 1997: 66)

However, Ramalho *et al.* (1997) argue that Portugal has limitations in its production and citizenship sphere, especially in terms of autonomy and self-regulation, as has been highlighted by the OECD report above. Inevitably this limitation results in the domestic sphere compensating for the shortcomings of the State. As Crouch (1999: 385) argues: 'the strength of family and local community compensates for a low level of welfare development.' This dominance of the domestic sphere is, as has been discussed, particularly characteristic of familialist welfare regimes.

There is also limited state provision of community care services in Portugal, where the family is at the forefront in this area (OECD, 2003). In addition, Portugal experiences significant levels of sectoral dualism, where state employees and those working in private companies with generous benefits tend to have more generous welfare coverage than the rest of the population. The Portuguese state offers little or no provisions in the form of social assistance or action. Instead they run competitions for NGOs or Private Institutes of Social Security (IPSS) to apply for funding. The government sets out target areas for social action and the voluntary/private sector organisations get their funding by competing and fulfilling the criteria ascribed to that target area. Hence, certain groups or areas are given preference over others depending on policy priorities, and this can depend on the governmental cycle. The IPSSs which receive funding sign a protocol for action with the state, or the responsible party within social security in order to secure their funding. These protocols are then renewed on a yearly basis.

Traditionally, welfare regimes are characterised in terms of the state, family and the market. By contrast, there is very little attention given to the voluntary sector or civil society, which is a prominent area in Portuguese welfare provision. Boaventura Sousa Santos (1994) highlighted that civil societies are distinct from the state, if not oppositional to it. If there is high de-commodification, i.e. reliance on the state rather than the market, then there is a weak civil society. Alternatively, there tends to be a

stronger, more autonomous and self-regulatory civil society, if the state is highly commodified. The level of state intervention defines the extent to which civil society exists, as it attempts to fill its welfare gaps. In this sense the state and civil society are isomorphic. In the case of Portugal, the state sponsors and relies on its civil society. Sousa Santos speculates that the consequence of this is that one cannot operate without the other. However, because of the relative autonomy of each sector, there is a shortfall and instability between the two.

Together, these characteristics depict a clear distinction between Portugal and corporatist welfare regimes. This thesis wishes to explore and challenge the conceptions and, moreover, the existing welfare structure within Portugal. In particular, by viewing social policy as the principal means by which welfare is structured and administered, this study seeks to look at this process. As a result, this thesis not only focuses on key decision-makers within the state, but also key entities within civil society, as they are the main instigators of the policy process within Portugal. The following section will establish the approach this study intends to take regarding policy and practice.

2.3 An Alternative Approach to Policy and Practice: A Social Psychological Perspective

Deborah Stone (1984) explored conceptions of disability in the context of welfare structure and development. She argues that within society ‘the work system can never meet even the most minimal needs of many people’ (Stone, 1984: 16). In her particular case, she is referring to the shortcomings of a labour-based welfare state for those who cannot work such as disabled persons. Stone refers to the ‘distributive dilemma’ within the welfare state, which is based on two distributive principles: work and needs. The tension at the root of this dilemma is that of a ‘rules-based system’ conflicting with a ‘need-based system’. Whereas the rules-based system refers to the allocation of goods and services through principles that are not based on needs (e.g. cost-benefit analysis, resource management, etc), the needs-based

approach is. The distributive dilemma and the course of action it chooses are, according to Stone, what characterises the welfare state. Hence, the decision-making on what course of action to be taken is what makes up policy.

Social policy has proven to be a hard concept to define in terms of its functionality, and many theorists such as Richard Titmus (1974), and T. H. Marshall (1975) have attempted to offer such a definition. Adding to Stone's (1984) distributive dilemma, the academic literature has discussed and emphasised the importance of decision-making in shaping social policy. As stated by Hill and Bramley, social policy is 'virtually synonymous with *decisions*' (Hill & Bramley, 1986: 3). However, they argue that individual decisions alone do not constitute policy. Policy is rather a process of decisions, or even decisions made as a result of others. These decisions are made by political actors, including not only politicians, but also other members who make up the policy sphere, such as civil servants, etc. As Fulcher (1989: 5) argues:

The traditional framework with its top-down model of policy (government makes it and its bureaucracies implement it) was clearly false: if by policy we mean the capacity to make decisions and act on them (power is implied here, so this is a political model) ... policy is made at *all levels*. - (Fulcher, 1989:5)

Fulcher takes a similar stance to that of Hill and Bramley (1986) in that the different decisions taken and executed at different levels can together be classified as policy-making. Although it may be the government that establishes the policy agenda, certain 'bureaucracies' are also influencing policy. These bureaucracies, such as the civil service and/or welfare providers, play a key role in implementing and even defining policy. They influence the direction it takes with each decision made. As Fulcher, argues, 'discourses articulate the world in certain ways: they "identify" "problems", perspectives on those problems and thus "solutions"' (Fulcher, 1989: 9). There are various factors that influence a decision, and how one applies and implements policy. Fulcher herself, in exploring disability in the context of education, observed that the different identities and needs of each individual within the policy process affected their decisions. These decisions can sometimes conflict with other entities in the policy process that have different priorities and needs if not

roles, making the policy process a complex interplay of actors and an amalgamation of different policy decisions.

Within the policy process, there are various levels and forms of policy implementation, ranging from the government to street-level bureaucrats. Lipsky (1980) explored the role of street level bureaucrats. He defined Street-level bureaucrats as:

Public service workers who interact directly with citizens in the course of their jobs, and who have substantial discretion in the execution of their work are called *street-level bureaucrats*. - (Lipsky, 1980: 3)

The substantial discretion referred to by Lipsky is what gives the street-level bureaucrat a substantial amount of flexibility and hence power in making decisions on policy-related issues. Furthermore, as Drake (1999) notes, ‘civil servants and other officials may take an approach related more to professional identity than to political expediency’ (Drake, 1999: 23). How one identifies one’s job and professional role, affects his/her conduct. The professional conduct of policy decision-makers will influence their decisions regarding their work, and hence policy outcomes. Although from a top-down perspective written policy can be viewed as a political decision, the application may result from a professional decision made by bureaucrats at a lower level. Each role has different priorities and different identities associated with these priorities. Lipsky (1980), for example, discusses that managerialism is more concerned with cost-effectiveness and optimal performance. Although managers may not have a direct contact or impact on the citizen, in terms of policy implementation (as street-level bureaucrats do), they have an indirect role as the coordinators of street-level bureaucrats. Managers limit to a certain degree the amount of discretion which street-level bureaucrats have, and supervise their performance in implementing their policy decisions. Managerialism, hence, indicates another level in policy-making, with possibly different environmental variables from that of the street-level bureaucrats. In summary, different roles entail different priorities, and different priorities entail different approaches to policy.

As a result, these different approaches can lead to certain variations in policy outcome. Drake (1999) pinpoints three main reasons for this, which are listed below:

- Policies arise from different departments, at different times and, as such, may be contradictory in nature, making it hard to comply with all policies at the same time
- Inconsistent policy guidance from the central government leads to operational decisions being made at local level, which may result in variations in application
- Decisions involve a different number of players with differing priorities and approaches, which again may result in differing applications (adapted from Drake, 1999)

As highlighted above, policy is the result of a process of decisions; decisions that are made at various levels, within different contexts. Because there are various individuals involved within this process, from various different departments and areas, it may limit the extent to which policy practice is uniform and consistent. Having this discretion is not necessarily a disadvantage, since needs and issues are not uniform throughout the state and hence require tailored and differentiated responses. The problem lies in whether the balance differentiated responses is addressed effectively. In the previous section, it was mentioned that Portugal is in its early stages of decentralisation, with a significant proportion of the civil service found in the central administration. This renders the distribution of the civil service uneven. As discussed above by Drake, inconsistent policy guidance from central government leads to operational decisions made at local level. This structure can often result in variations in application. Furthermore, being in the early stages decentralisation can result in Drake's analogies above, not to mention Portugal's constantly changing government. These changes could limit and add confusion to policy guidance and objectives. Finally, as discussed above, there are various political players in the policy process, with differing priorities and approaches. This too can result in differentiated policy applications.

Social psychology provides an effective approach to explore these differentiated policy applications. Carroll (1993) drew upon various elements of his previous 'lab' based studies, to elucidate an understanding of decision-making in organizations. In his work with Payne (1977), a schematic difference was noted in responses between two groups who undertook his research: experts and students. Schemas can be viewed as mental frameworks that organize social information that we encounter in

everyday life (Baron et al, 2006). Carroll and Payne (1977) found that, while experts had real experiences on parole matters and therefore more detailed schemas, students only had the general information presented to them within the study and no preset mental framework in this area. In addition, Carroll and Lurigio (1985) researched probation officers, where they conducted interviews identifying types of probationers and their characteristics. It was found that probation officers reported between 3 and 9 different schemas, and a third of the officers reported 10 (Carroll, 1993:49). In follow-up studies, they found that cases constructed in order to correspond to schemas were tackled more effectively than real cases or cases corresponding to mixed schemas. Furthermore, Carroll identified that the more experienced probation officers seemed to have fewer schemas and less idiosyncratic ones. As a result, Carroll found that those with predetermined schemas on a subject will tackle problems more quickly, effectively and presumably correctly than those who do not. The presence of strong schemas may lead individuals to disregard falsifying information. Consequently, problems that may be similar, but which could be tackled and interpreted differently, will often be approached in the same fashion.

What further information do these studies tell us? Firstly, they seem to indicate that given our social influences and experiences we construct different schemas, and schemas may differ depending on experience and exposure we have to a particular area and information, and the continuity of exposure. As illustrated above, experts on parole decision-making have more specific responses to this area than students. Similarly, students probably have more specific responses to study skills or library exercises than experts on parole. This is due to their continuous exposure to these areas. Secondly, even experts differ in their schemata, just like students differ in study skills approaches. In the case of parole officers, their response to particular cases correlated with their correspondence to preset schemas. Hence, these factors reflect a schematic interpretation of how our consciousness can be determined by their social existence.

This thesis wishes to explore the differentiated schematic approaches that key decision-makers may have associated with policy decision-making regarding

children with disabilities. It seeks to understand the individual within the policy process and how she/he executes policy and has a social psychological basis to its approach. As highlighted above, different individuals have different roles and priorities, and different schemas each unique to that individual. As a result, this thesis seeks to adopt an approach that allows us to explore the individuality of each policy decision-maker within the social psychological context. The concept of identity relates to the way in which one defines oneself and hence how one acts and thus provides an effective tool for researching the unique approaches of each individual policy decision-maker. The following section shall explore conceptions of identity, and construct an approach to explore policy decision-making.

2.3.2 Constructing Identity

Identity is a complex issue. On the one hand, it can refer to ‘sameness’ where one feels one belongs to or ‘identifies’ with a particular concept, ideology, group or persona (Jenkins, 1996). On the other hand, it can refer to difference, where one possesses a unique identity. Goffman’s (1969) conception of the ‘Presentation of Self in Everyday Life’ portrays the individual as an ‘actor’ playing a role in the theatre we call ‘life’. The actor’s performance is led by his/her perception of their audience and the reaction the ‘actor’ intends to provoke in that audience. Given that social beings encounter, and are part of, different social settings, they play a different role in each setting. For example, one can be a father, a civil servant, a football supporter, a driver, and so forth, where different settings will evoke different performances specific to each role. Sparks (2000) has noted that we have varying ‘selves’ in his account of the ‘utility of self-identity’. He claims we are a product of the society we live in, where our social influences construct who we are. This illustrates that there are different methods by which identity can be generated and in turn perceived.

In social identity theory and identity theory, the self is reflexive in that it can take itself as an object and can categorise, classify, or name itself in particular ways in relation to other social categories and classifications. This process is called *self-categorisation* in social identity theory ... ; in identity theory it is called *role identification* ... (Stets and Burke, 2000: 224)

Within the existing literature, there are two distinct schools of thought regarding identity: Identity Theory (IT) and Social Identity Theory (SIT). In short, IT views identity as a process of role identification and implementation within the self, whereas SIT views identity as the perception of belonging to a category or group (Hogg *et al.*, 1995; Stets and Burke, 2000). As illustrated above, the main processes in which identity is formed are role identification for IT and self-categorisation for SIT (Stets and Burke, 2000). Yet, there is much debate and controversy surrounding this simplified distinction.

Hogg *et al.* (1995: 265) argue that these theories run in parallel, originating in and being structured around theories emanating from two distinct fields: social psychology (IT) and sociology (SIT). However, this is not to say that they must remain hermetically sealed from one another. As highlighted above, one theory is concerned with how one defines oneself, where as the other defines how one will act according to these self-definitions. Hence, it is possible to combine the two approaches in order to formulate a new theory as they follow on from each other. In terms of policy, this could prove to be an effective analytical approach. Together they will explore what areas and categories one identifies with regarding policy decision-making (categorisation) and also how one will address these areas (role identification). This section begins by analysing the key characteristics of both of these theories, before examining the possibility of amalgamating the two to create a new theory that can be applied to my data analysis.

2.3.1.1 Social Identity Theory

SIT has certain similarities to Goffman's (1969) idea of 'performances' in 'The Presentation of Self in Everyday Life.' The *performance* is led by the actor's perception of his/her surroundings and the reaction the actor intends to provoke in others, or rather, the group of which she/he is part. Similarly, SIT revolves around inter-group membership and performance. One's identity is based on self-categorisation. However, what this entails is that one identifies with a particular categorisation, such as a teacher or father or even certain characteristics or actions such as 'being professional'. These categories can be seen as groups, as there

numerous people who are teachers and/or fathers, all these people within this category, share an identity category. In addition, as people tend to choose or identify with certain categories over others. After all, one cannot be everything at all times. As a result, one associates more with one group over another (Hogg *et al.*, 1995), and hence a cognitive prototype (or way of thinking) that that group represents. One will act according to the group one identifies with, and the perceptions one has of a particular role as it relates to membership of that group. Although Turner (1987: 67) introduced self-categorization as a means by which to further understand group-based behaviour in social psychology, this theory has become synonymous with SIT, (Hogg *et al.*, 1995 *inter alia*). This process is viewed as a form of depersonalization (see Turner, 1987 and also Hogg *et al.*, 1995) where one loses individuality by associating with a group and its perceived norms.

2.3.1.2 Identity theory

Hogg *et al.* (1995: 259) highlighted IT as having 4 main characteristics. Firstly, IT takes a social psychological viewpoint of the self. The self is viewed as being defined by social factors and surroundings. In other words, individuals have socially constructed personas. Secondly, this social construction has defined preset structures within the social world. People operate within these structures and adopt associated roles. By associating with and fitting into different roles, we construct who we are. Thirdly, as elaborated above, IT is based on role identification. Accordingly, roles may vary based on their attributed importance. Through this process of identification, one selects the role that seems the most appropriate at any given time. Consequently, one transmits the sense of self through the roles one chooses. IT mainly focuses on processes of identification and the outcomes of the relationship between the self and society. Our social being or the way in which we view ourselves, is defined by the existing social structures and how we see ourselves fitting into and/or accommodating ourselves within them. IT does not concern itself with the socio-cognitive struggle to find one's identity, but rather how one selects, gives preference to or adapts one's identity to pre-existing sets of roles or identities presented to us.

2.3.1.3 Constructing an Identity Theory Applicable to Policy Decision-making

George Herbert Mead (1934) is renowned for his work on conceptions of the self. His me/I complex highlighted that there were two parts to the self, the me and the I. The 'me' refers to the socialised self, which emerges through the association with others. The 'I,' meanwhile refers to the active self, or the self that makes active decisions. Together these conceptions form the self. Although Mead (much to his dismay) is now identified as being associated with the field of social psychology (Carreira da Silva, 2007) and places heavy emphasis on role-taking, he also places emphasis on the identification and the process of adopting the role of the other, or acting in terms of what one perceives is expected of them by the other. This analogy of the self has elements of both IT and SIT, highlighting that by combining the two theories it is possible paint a more complete picture of the self.

From the above descriptions of IT and SIT, one starts to view the social psychological and sociological content of these theories. From the IT perspective, one can view the sociological element in the social structures in which one operates and identifies oneself. However, the process of identification does highlight elements of interpersonal or cognitive process, and hence elements of social psychology. Similarly, SIT reflects social psychological thought through the process of self-categorisation. However, through depersonalisation and focusing on group dynamics, it suggests elements of sociological thought. Hogg *et al.* (1995) stated that one of the main ways in which these theories differ is that they belong to different subject areas. However, there is no clear defining line or division between subjects, and their borders are often blurred. In fact, these theories are similar to the point they transcend their subject areas and overlap to a large extent.

Regarding the differences between the two theories, Hogg *et al.* (1995) stated that SIT does not discuss roles, as such, but it would probably consider them when referring to positions within a group. They place a great emphasis on SIT being concerned with group dynamics in defining identity and conduct. Although Hogg *et*

al. do touch upon the impact of roles in the group context, there is a preference for acknowledging one's role as a 'position' within a group rather than a role as such. This analogy attributes a status to the individual, but ignores the contextual role resulting from having this position. They criticize IT for not being socio-cognitive enough and its belief that self-definition emerges from roles rather than oneself. Only when linked to group norms and membership are one's behaviour and attitudes assessed. However, having a role entails a preset code of conduct and a set identity associated with that role. This identity and the role it entails is unique to those who possess it. It seems that the debate between SIT and IT is linked with active and passive identity. Whereas SIT characterises identity as being an active process where one actively chooses and adopts one's identity and exercises it, IT seems to take a more passive approach. Identity is a result of social conditions and circumstances.

In terms of the similarities between the two theories, Stets and Burke (2000) suggest this fusion; of who one is (SIT) with what one does (IT), and that this fusion is beneficial to the field of social psychology at all levels, whether macro, meso or micro. They recognize the similarities of the two theories, and go on to state that:

...one's identities are composed of the self-views that emerge from reflexive activity of self-categorisation or identification in terms of membership of particular *groups* or *roles*. - (Stets and Burke, 2000)

The process of depersonalization through self-categorisation is very much similar to that of role identification, both are identifying with a persona. Furthermore, having certain self-views and identities entail acting and reacting in a certain fashion. As Stets and Burke indicated, the theories are substantially more similar than is often believed. Role identification too, like SIT, suggests an inter-group approach, but from a reciprocally interactionist perspective. Rather than breaking down surrounding structures into in-group/out-group statuses, role identification explores the relationship of an individual with his/her surrounding social structures. By amalgamating both of the theories, one could provide a more all-encompassing theory that can be applied to the data analysed in the current project. As Stets and Burke suggest, it is possible to explore the data from a categorical and role

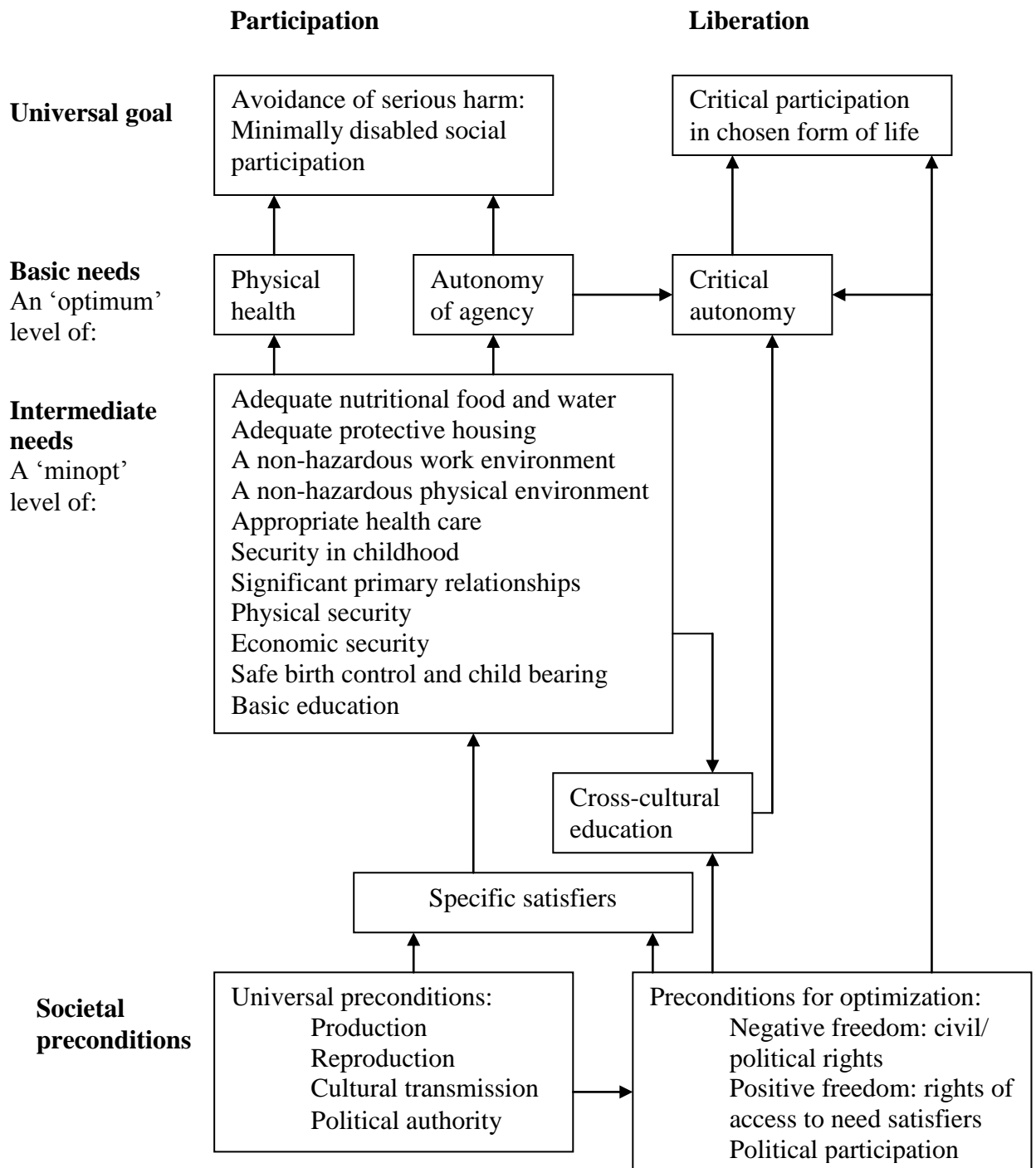
identification perspective, where both are equally effective means of analysis. However, by combining the two one can explore a wider range of policy decision-making.

When researching one's identity at work and how it impacts on decision-making, it is important to not only take into account how one sees oneself but also what one's role is and how this is perceived by the individual in question. Thus, a combination of SIT and IT is more appropriate in tackling these research objectives than either of these theories alone. By combining the two, one can not only explore who an individual believes s/he is, but also her/his actions that result from this self-conception. In addition, it allows one to explore active and passive thought-processes. If one is to explore the individual schemata associated with this area, one can explore how these schemata affect decision-making, and influence one's identification of implementation areas and approaches. This merger could be an effective tool in researching the policy process by unmasking the core of the decision-making process, the decision-maker themselves. This thesis intends to explore this identification process, and the extent to which it accounts for the variation in policy outcomes. In addition, this thesis has opted to focus on policies regarding children with disabilities, in order to challenge this identity-based approach. Children with disabilities are a social group that do not fully share an identity with the policy decision-makers, and although these two groups may have things in common, they do not have identical identities. Hence, the current project is interested in exploring how individuals make decisions for a social group with which they have very few if any shared experiences. The following sections will analyse the concept of 'children with disabilities' by dealing in turn with the sub-categories of disability and children, which constitute it. These sections shall explore the conceptions of these categories in order to better understand their conceptualisation and the way in which they relate to the umbrella category of children with disabilities.

2.4 The Concept of Disability

The kinds of problem which people experience; requirements for some particular kind of response; a relationship between problems and the responses available. (Spicker, 1995: 268)

Having a need for something usually implies a lack or a demand for of a specific good or service. According to the above definition, however, 'needs' can also be viewed as the requirement of a solution for a particular problem. Spicker (1995: 39) argues, for example, that 'because problems are often social, needs are too.' The implication of this is that needs are often socially constructed. Gough (1998: 53), too, places needs in a social context, arguing that basic needs are universal prerequisites for participation in a specific social context. Hence, basic needs are those orientated at enabling us to participate fully in society. In addition, he states that these prerequisites are autonomy and physical health. Therefore, basic needs are the ability 'to make informed choices about what should be done and how to go about doing it' (Gough, 1998: 53), and to have the physical ability to put these choices into action. In the diagram below, Gough and Doyal (1991) present us with a theoretical model on the structure of needs within society.



(summarised in Gough, 1998 :51)

According to the diagram above, the universal goal of the individual is to be able to participate fully within society, and to be able to follow one's choices within society, whether political, professional or personal with minimal restrictions (provided, of

course, that this does not involve any harm to others). This can only be attained, however, if there are the societal pre-conditions for such. Once these pre-conditions have been established, needs such those listed above under the rubric of 'intermediate needs' become arise. It is important to point out that, according to Gough, needs such as food and shelter are in fact intermediate needs, whilst basic needs refer to the ability of an individual to attain and make use of them in order to engage in social participation. Although seemingly straightforward, and taken for granted by many, these prerequisites are not available to all. Gough himself has noted the difficulties encountered by persons with disabilities within these areas, in which their basic needs are more prominent than those of 'able-bodied' persons. Children too, can also encounter the same difficulties for similar reasons. Their needs are more prominent than those of adults.

Mike Oliver has been a revolutionary figure within the field of disability studies. He divided disability into two different models: the individual model and the social model, which resonate throughout the disability related literature. The individual model (often referred to as 'medicalisation'), which was the traditional western approach to disability, was described as 'the personal tragedy theory of disability' (Oliver, 1996: 31). This theory views disability as the liability of the individual who possesses it, and the role of provisions is to aim at aiding the individual to adjust to their impairment, and rehabilitate him/her. This view extends from the ideal of 'normalcy' and how the disabled person compares with such an ideal. On the other hand, the social model views disability as an imposition of restrictions and 'social barriers', 'ranging from individual prejudice to institutional discrimination' (Oliver 1996: 33). These 'social barriers' refer to the various physical and social environments, which limit the participation of those with disabilities in society. This approach to disability makes society responsible for 'disabling' the individual and, as a result, provisions are aimed at correcting society rather than the individual. This requires needs to be met in the 'autonomy' sphere, referred to by Gough (1998) and, hence, making one autonomous.

In a similar vein to Oliver, Stalker *et al.* (1999) also divide disability into two separate models. However, instead of the individual model, they introduce what they call a 'normalisation model'. The normalisation model also compares people with disabilities to a 'fictional' normality that presumably 'able-bodied' people have, and aims to integrate people with disabilities into society. The social model, on the other hand, aims to adapt society to meet the needs of people with disabilities. This distinction is also present in other approaches to disability, such as the inclusion vs. integration debate. Save the Children, for example, produced a report in 2002 on inclusive schooling. Within this report it highlights that integrative measures are orientated at rehabilitating the child or making her/him adapt to the school's educational measures. On the other hand, inclusive measures are based on changing education in order to meet the child's needs. Whereas integration refers to normalisation, inclusion refers to the social model, where inclusion and the social model are deemed the more attractive option.

However, there is much debate within the social model spectrum. There are those who argue that a 'commonality of disability' should be the core of the disability movement (Morris, 1991; Finkelstein, 1993; Priestley, 1999), meaning that disability should be addressed in the social context. Since it is society which is disabling, people with disabilities, regardless of the nature of their disability, suffer the same oppression. The assumption within this body of thought is that this shared social oppression needs to be addressed and differentiating between different forms of disability, will simply result in the type of policy response associated with the medical/individual model.

On the other hand, Liz Crow (1996) suggested that impairment should be included in the social model.

What we need is to find a way to integrate impairment into our whole sense of selves for the sake of our own physical and emotional well-being, and, subsequently, for our individual and collective capacity to work against disability. (Crow, 1996)

Crow stresses the need to deal with and encounter impairment. In terms of disabled persons, the social oppression extends from the impairment one has which is deemed disabling. By confronting the impairment, one can address the nature of the barriers encountered and furthermore overcome the disability and the 'disabling' environment within society. As rightfully suggested by Crow, other oppressed groups within society, are oppressed over aspects such as skin colour, religion, gender, which are not necessarily physically limiting and painful. A person with disabilities, on the other hand, is not only oppressed by her/his surroundings (as suggested by the social model) but also have the personal experience of her/his disability. By ignoring impairment, one is essentially ignoring the root of the conceptualisation of 'disability' within society and the very nature of the way in which the barriers they present are disabling.

It may be possible to argue that by considering impairment, one may be bringing back the medical model through the back door. However, it seems the problem lies in the conception of how to approach impairment and disability, rather than the word 'impairment' itself and perhaps that misconception needs to be addressed. Following Crow's argument, Shakespeare and Watson (2002) criticise the social model for trying to overlook impairment and, thus, for disregarding the personal experiences of disabled persons. They state that '[d]isability cannot be reduced to a singular identity: it is a multiplicity, a plurality' (2002: 19). In other words, the disability arena comprises a multitude of differing characteristics, ranging from a variety of impairments.

In addition to the 'bringing in impairment' debate, there is another issue that needs to be addressed in terms of the conceptualisation of disability. Sim *et al.* (1998) conducted a study on whether disabled persons and care professionals could agree on defining needs. They based their research on issues arising out of the Community Care Act (HMSO, 1990), and their criteria were structured around the Individual and Social model of disability.

As part of their rationale for their study, the following diagram was presented in order to analyse how his participants conceptualised disability:

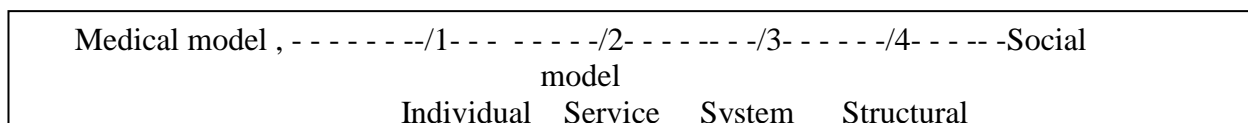


FIG. 1. Locus of control model (Sim *et al.*, 1998: 60)

This ‘locus of control’ deconstructs disability into different stages and/or areas in which disability and disability-related needs can be addressed and/or identified. It starts with the individual stage, where disability is associated with the individual, and services are aimed at catering for impairments. The service stage focuses on addressing the services directed at the individual. The system stage, on the other hand, focuses on the coordination and management of the services directed at the individual, whilst the structural stage takes the system stage to a more abstract level that is based on rules, written policies and systems. What the locus of control model does is take the conception of disability a step further in recognising that disability like policy happens at all levels. This model meshes the individual model with the social model. It also provides an effective measure for analysing disability-related policy and the policy process. It allows one to view where the most significant disabling barriers lie.

This thesis aims to apply these different models to the data analysed here, as together they incorporate a comprehensive approach to disability. Consequently, this thesis will not only assess whether there is an individual or social model of disability within Portugal, but also what approaches there are to policies. It will examine whether the normalisation or social model best describes the Portuguese approach to disability and whether the aim of these policies is inclusion or integration. In addition, this thesis shall explore at what area and/or level listed above are policies and decision-making targeted.

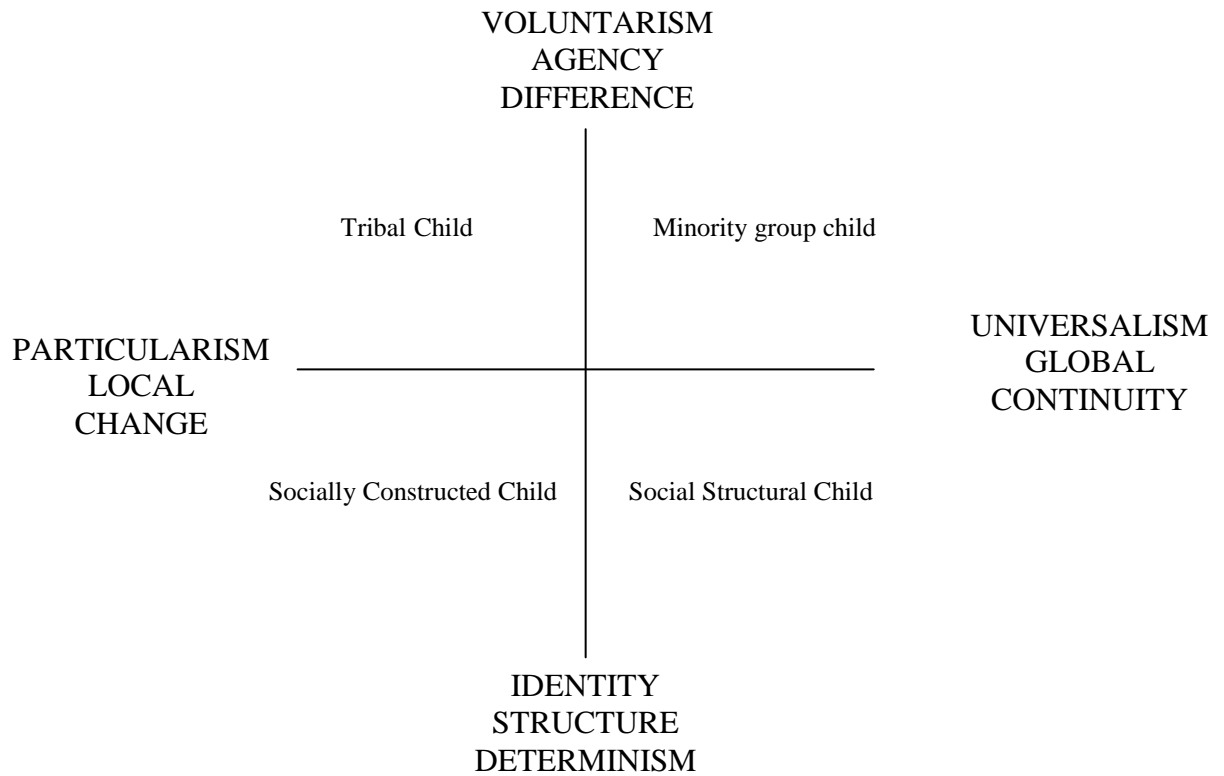
2.2 Children

Whereas the term ‘disability’ refers to a type of condition or experience, the term ‘children’ refers to a type of person. Childhood is complex topic. It is a multifaceted area incorporating differing conceptions and contexts. According to James *et al.* (1998) in a sociological context, childhood has been deconstructed and explored in 4 main ways:

- Social structural – where childhood is view as a category that can be generalised. According to this approach, every adult has been a child and most children will grow to become adults. Childhood is viewed as a permanent facet within society that is universally accepted and recognised.
- Minority group – where children are viewed as politicized, active and conscious beings. In accordance with the social structural approach, this group also views childhood as a universal facet of society. It is understood that children are a social group whose needs and interests vary depending on nationality, culture and setting. This area also views children as an oppressed and hence a minority group.
- Socially constructed – where childhood is viewed as a form of discourse. The concept of child is socially constructed and relative to the surroundings she/he is found in. The concept of child is temporal and ever-changing.
- Tribal - this approach involves a more anthropological conception of childhood, and sees children as having their own social worlds, rituals and structures that are unfamiliar to the adult eye. (James *et al.*, 1998)

James *et al.* (1998) also note that these categories are not exclusive, and can even overlap, nor is there one unique way of theorising childhood. Nonetheless, the definition above proves quite helpful in comprehending and conceptualising childhood, and diminish the complexity of this category. They delineate how childhood is a multi-faceted concept and highlight areas in which some of these facets exist. Children are not just fixed universal identity within all societies. All children are unique and possess their own opinions, beliefs and identities. This variation can be explored in a multitude of contexts. James *et al.* (1998) argue that the above categories correspond to four of the major philosophical paradigms within social theory: voluntarism, determinism, universalism and particularism and thus constitute a theoretical field for the social study of childhood.

Theoretical Field for the Social Study of Childhood

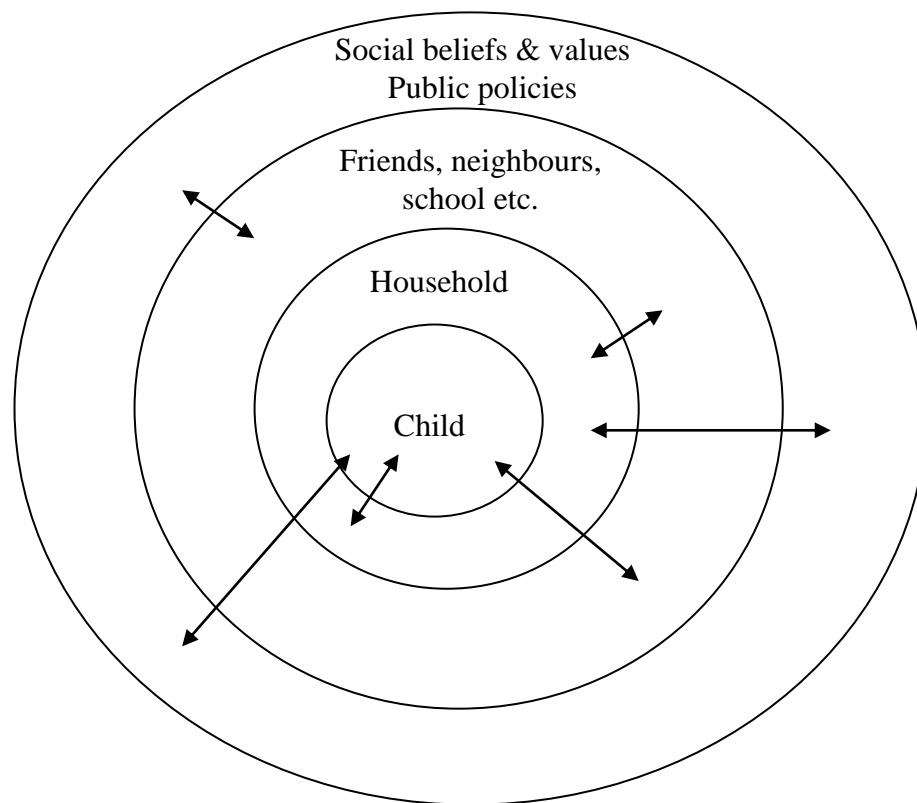


(James *et al.*, 1998: 206)

By incorporating these four paradigms into the context of childhood studies, one can explore the problematic dichotomies that exist in this field of analysis between structure and agency; identity and difference; local and global and, finally, continuity and change. This diagram shows how one can map these issues on to debates within disability and childhood studies. The approach this thesis chooses to adopt is to focus on how children and in particular children with disabilities are socially perceived by others, and not how they are in a purely physical sense. Hence, it explores the interplay between identity and difference.

How key decision-makers within the Portuguese civil service view and understand children with disabilities, and which of the areas above they fall into (if any), is the main centre of focus of this research. In particular, it focuses on how key decision-

makers identify with children with disabilities and, hence, how this identification impacts on their decisions regarding the child's welfare in the context of social policy. Hill and Tisdall (1997) illustrated the complexity of children's relationship with society and the social world. As can be seen by the diagram below, children can have various protective (social) layers surrounding them.



(Hill and Tisdall, 1997: 4)

From the diagram above it is clear that children have various social layers sheltering them and interacting with them, before they come to engage (if at all) with elements relating to public policy. As stated by Hill and Tisdall (1997), the most important relationships that most children have are with close relatives and other children. Similarly most welfare provisions that children encounter are within the household and school setting; they do not usually interact directly with the state.

Archard (1993) argues children live distinct parallel lives to that of the adults surrounding them. He states that children are seen as separate from the adult world, and are unable to participate fully and individually in the ‘adult world’ of politics:

The particular nature of children is separate; it clearly and distinctly sets them apart from adults. Children neither work nor play alongside adults; they do not participate in the adult world of law and politics. (Archard, 1993: 29)

However, as illustrated above, there are various ways in which children are viewed and that this parallel status is more of a ‘intergenerational’ phenomenon. The extent to which children are engaged in adult life and politics and how they are viewed, can be very much reliant on the welfare state they live in. Portugal has a familialist welfare structure, which means that the State is reliant on the domestic space for welfare provision. Hence, it is not structured to engage directly with children in the policy arena, but rather it is structured around the main breadwinners in the family and around civil society. Moreover, the focus is on carers within the family to care for their dependents, i.e. children and family members who are unemployed and/or disabled. By its very nature, this welfare regime already predetermines the lack of political engagement of children, regardless of the global understanding and objectives for childhood and politics. Hence, in the context of policy and in terms of James *et al.* (1998) there is a local particularistic way in which children will be perceived and addressed. In addition to identity/difference distinction, this thesis will also explore particularism in the context of the policy process regarding children with disabilities. It will also examine which of the spheres identified in Hill and Tisdall’s diagram (i.e. the child, household, friends, neighbours, school, social beliefs and values) policies are orientated at and structured around.

Not only do children with disabilities encounter the same barriers (or rather of adult behaviour, bestowed upon them) as other children, they also encounter the ‘barriers’ presented to disabled persons. As argued by Marchant:

Children’s impairments can of course create genuine difficulties in their lives, but many of the problems faced by disabled children are not caused by their conditions or impairments but by societal values, service structures or adult behaviour. (Marchant, 2001: 217)

The question is in where the balance lies, in terms of bringing in these conceptions together. Are children with disabilities more like ‘people with disabilities’ or are they more like ‘children’ in terms of the barriers to social participation with which they are confronted? Consequently, it is important to incorporate and amalgamate both perspectives when researching this topic and to assess the relative importance of each. The analytical framework developed here shall be discussed and developed further in the methodology chapter.

2.3 Concluding Remarks

This chapter has explored the various premises on which this thesis is based and the main bodies of literature to which it aims to contribute. In viewing social policy as a decision-making process, this thesis is interested in looking at the primary actor in these decisions: the decision-maker. It is interested in decision-makers’ identities and how these impact on their decision-making. This chapter discussed two theories within the sociological/social psychological field that explore identity: identity theory and social identity theory. Whereas social identity theory looks at how one categorises oneself and identifies as belonging to a particular group, identity theory looks at identity as a process of role identification. This chapter found that a combination of the two theories would be a more inclusive approach to analysing policy. Hence, this thesis would not only explore how decision-makers categorise themselves, but also the roles they identify with and adopt. This particular approach relates to Mead’s (1934) me-I complex, where the ‘me’ refers to the socialised self and the ‘I’ refers to the active self. Together, these two components form the self. By viewing how one categorises oneself and, in addition, how one acts within that context, one can build a picture of the self within that particular context. As discussed above individuals do not have a single, unitary identity, but rather a combination of identities that emerge within different contexts and in response to certain triggers and/or stimuli.

When focussing on children with disabilities, this chapter broke down this category into two separate fields: disability and children. Within the section on disability, two predominant models emerged. The first point of contestation centred on whether

disability should be seen as the responsibility of the individual or of society. Within this context, two approaches emerged: the normalisation model and social model. The second area of debate centred on how disability ought to be addressed in spatial terms. It was argued that it is inadequate to say simply that disability is caused by society. It is necessary also identify where and/or on what level these barriers lie. As a result, this thesis will not only explore what approach is taken towards disability in the Portuguese context, but also at what level of the policy process disability is addressed, when it comes to children with disabilities.

Finally, this thesis will also analyse what approaches are taken to childhood within the Portuguese welfare regime. As discussed above, there are various social layers surrounding children, meaning that they rarely interact directly with the State and that their needs are usually addressed by the social networks that surround them. Portugal has a southern European welfare model with a familialist structure, which suggests that the family is accountable for a child's welfare. This thesis will bring this conception of the familialist welfare regimes into its analytical framework and will explore where or to whom policies regarding children with disabilities are directed. Children with disabilities, it will be argued, have a differentiated relationship with the state than other children or adults with disabilities, and are subject to a different policy structure due to their particular needs. This chapter has set out the background for the present study and has discussed the aims and objectives of the project in the context of the relevant bodies of literature in the field. The following methodology chapter shall address how this will be done.

3. Methodology

3.1 Introduction:

The previous chapter highlighted the theoretical basis for this thesis, which explores how key decision-makers within the Portuguese civil service make decisions regarding policies orientated at children with disabilities. This thesis targeted policy advisors and implementers within the areas of Education and Social Security, as these were the areas highlighted by Portuguese country reports to the UN Committee on the Rights of the Child as being responsible for policies regarding children with disabilities. In addition, because of the heavy reliance of the Portuguese welfare regime on civil society, especially in the social action sphere, two representatives of two of the biggest disability-related voluntary organisations were also interviewed in order to better comprehend their role in conjunction with the state.

The previous chapter highlighted the manifestation of active and/or passive (or conscious and unconscious) identities and how they impact on decision-making. As was explained above, G.H Mead (1934) had a similar approach to self in discussing the difference between 'I' (active aspect of person) and 'me' (socialised aspect of person) which form the 'self'. It is this form of self, which this research project aims to explore. As a result, this thesis needed to employ a method (or methods) which could explore both the 'I' and the 'me' aspects of civil servant's identity structures. In the end it was decided to adopt interview and vignette methods as the most appropriate way of doing this.

Interviews were chosen because they allow one to explore the individual perceptions of childhood and disability and the way in which this impacts upon civil servants' conceptions of policy towards children with disability. It is possible to enquire and explore how and why a person has reached a particular decision. Vignettes, on the other hand, allow one to analyse an individual's approach to problem-solving and decision-making. The use of vignettes allows this study to explore decision-making. In addition to these methods, this thesis involves the analysis of written policies and

legislation. This was undertaken in order to establish the policy context in which the key decision-makers operate in.

3.2 The Participants

As previously mentioned in Chapter 2, Portugal is in the early stages of decentralisation, where the majority of the civil service is incorporated into the central administration. For this reason, this thesis will focus on the central administration, since it is the main body, at governmental level, concerned with policy-making.

Within the central administration, there are different Directorates General (D-G) within different ministries, which mainly have coordination duties within each ministry (Portal do Governo, 2007). As was explained in the previous chapter there is a lack of coordination and communication between the different tiers of the State administration within Portugal, especially in terms of budgeting (OECD, 2003). Assuming that policy is a complex network or process of decision-making, which takes place at different levels and in different departments, inconsistencies in communication and coordination will clearly impact on how decisions are made. By looking at the D-Gs whose main functions are coordination, one can view this process in action. In the sphere social security and solidarity, the Directorate-General for Social Security (DGSS) is responsible for the conception and coordination of policy as well as normative guidance and technical support (Segurança Social, 2005). For education, the Directorate-General for Innovation and Curricular Development (DGIDC) also has coordination/normative role.

In addition, this study also involved interviews with functionaries in the managerial areas of the civil service that dealt with the implementation of policies. The Institute for Social Security (ISS) is the department that manages the Social Security regime, measures of Social Action, as well as implementing international measures of Social Security (Segurança Social, 2005). The Regional Directorates for Education (DRE) have responsibility of orientating, coordinating and supporting educational structures that are not specific to higher education. The DRE is divided into five geographical

districts: Tagus Valley and Lisbon, North, Centre, Alentejo and Algarve. This particular study focuses on the Regional Directorate for Education of Lisbon (Direcção Regional da Educação de Lisboa: DREL) due to it being geographically close to the central administration. As illustrated above, one of the main functions of these D-Gs is coordination which, according to the OECD, is an area in which the Portuguese State administration falls short. Consequently, it is interesting to study how this unit within the government is structured, and how it influences policy action.

In addition to these D-Gs, this study also involved interviews with a specialist within the National Secretariat for the Integration and Rehabilitation of Persons with Disabilities (SNRIPD), which is one of the main units within the civil service handling disability-related areas and policies. At the time of the data collection, SNRIPD was attached to the Ministry of Employment and Social Security. However, this Secretariat has an unstable position within the civil service in terms of its supervisory body, as it has been subsumed within various different ministries at different times in its history, at one stage falling under the direct remit of the Council of Ministers.

Within Chapter 2, it was argued that the Portuguese welfare state relies extensively on civil society and is involved in sponsoring private and voluntary organisations (the so-called IPSS) in the field of social security. As a result, interviews were conducted with representatives of the administrative and managerial bodies within two of the largest disability-related organisations: the Association for Persons with Disabilities (APD) and National Federation of Cooperatives for Social Security (FENACERCI). Whereas, APD is involved in lobbying and awareness-raising about disability related issues, FENACERCI works alongside the Government and provides services orientated at people with disabilities.

The following sections explore each of the entities highlighted above in further detail. It is worth mentioning at this stage, however, that every organisational unit that was contacted was given a letter (see I. Appendix) highlighting the aims and

objectives of the present study, a list of the main interview questions that were to be asked, and a copy of the vignette (with the exception of the interviewees from the private and voluntary organisations, as they were not central to this aspect of the study). Given the difficulty in obtaining access to high level decision makers and civil servants, it was not possible to choose specifically which individuals from each department or organisation would be interviewed, although every effort was made to interview all the specialists on disability policy within the above institutions. Ideally, it would have been desirable to interview all the relevant specialists in each department or within each institution. However, most of the institutions only allocated one person to be interviewed stating that this was the one specialist that could provide information relevant to this study. Consequently, interviews were conducted with the informants that were allocated to this study, because of their particular expertise in the area of children with disabilities and also because of the restricted access to other potential interviewees. Furthermore, this allocation process also provides insight into how policies regarding children with disabilities are dealt with. It is important to note that all interviewees within the civil service were women, whilst both informants from the private/voluntary sector, by contrast, were men.

3.2.1 Directorate-General for Social Security (DGSS)

As a result of the Legal Decree 5/2005, passed on the 5th of January 2005, the Directorate-General for Social Security (DGSS) became the Directorate-General for Social Security, the Family and the Child (DGSSFC). This change was brought forward by the Ministry of Social Security, the Family and the Child under the former Social Democratic Governments in power between 2002 and 2005. Its main function is to conceptualise and give technical and normative guidance within the areas of social security and the 'social action' available for the family and child, (Segurança Social, 2005). This change of name was the result of an ongoing debate between the Social Democratic and Socialist Governments. Whereas the Social Democratic party tends to centre social security around the family, and naming its ministries and D-Gs accordingly, the Socialist party tends to centre social security around employment, again reflecting this in the names of government departments.

Consequently, with the return to power of the Socialist party in 2005, the DGSSFC has changed back into the DGSS as a result of Decree-Law 211/2006, and falls under the responsibility of the Ministry of Employment and Social Security of the new Socialist Government. The DGSS is now integrated in the direct administration of the State. However, during the period of data collection the Decree-Law hadn't yet been passed and the DGSSFC remained. Consequently, the focus of this study is on the DGSSFC during the period of study between 2002 and 2005. The DGSSFC was divided into 10 sections, some with sub-sections, which are as follows:

1. Directorate for Social Research Services and International Relations
 - a. International Relation Services
 - b. Nucleus for Documentation and Disclosure
 2. Directorate for Institutional Support Services and Judicial Issues
 - a. Section for Registry and Criminal Records
 3. Directorate for Support to Integrated Social Action
 - a. Division for Social Action orientated at Children and Youths
 - b. Division for Social Action orientated at the Adult Population
 4. Technical Office for Adoption
 5. Directorate for Services orientated at Defining Regimes
 - a. Division for Profit Framework and Relations
 - b. Division for Non-Governmental and Voluntary Regimes
 - c. Nucleus for Complementary and Mutualist Regimes
 6. Directorate for Cash Benefits Services
 - a. Division of Common Regimes for Cash Benefits and Immediate Cash Benefits
 - b. Division for Deferred Cash Benefits
 7. Directorate for Services for Application of Regimes
 - a. Division for Administrative and IT Applications
 - b. Division for Informative Applications
 8. Technical Office for Analysis of Statistics
 9. Office for Management and Training
 10. Technical Office for IT
- (Segurança Social, 2005)

Following a preliminary interview with a gatekeeper, it was stated that the two main departments that should be contacted for the purposes of this project were the Directorate for Services for Application of Regimes and the Directorate for Support to Integrated Social Action. Following some persuasion, an interview with an informant in the field of international relations was also granted. The Directorate for Social Research Services and International Relations is a research based service, which aims at deepening the understanding of guidelines and applications in the social action sphere, (Segurança Social, 2005). This Directorate is divided into two sub-sections one is an International Relations division specializing in issues

regarding social security and action, the other is a base for research, analysis and disclosure of documentation regarding social security issues (Segurança Social, 2005.).

The Directorate for Support to Integrated Social Action, is divided into two sub-sections: one specific to children and youths, and the other focussing on adults. Again, this directorate provides services for conceptualising guidelines, policy planning, technical support and coordination. However, it also looks at the different methods of social action, the different needs integrated in the family, diverse methods of integration and expression of social groups, whilst taking great consideration for human dignity (Segurança Social, 2005).

The Directorate for services orientated at defining regimes, conceptualizes technical and normative support, namely in terms of the structuring of global regimes within the social security sphere (Segurança Social, 2005). This support focuses particularly on binding judicial relationships, the contributory judicial relations and legal and sanction regimes, as well as complimentary professional regimes within Mutualist Associations (Segurança Social, 2005). As elaborated above this D-G is divided into 3 divisions: the Division for Profit Framework and Relations, the Division for Non-Governmental and Voluntary Regimes and the Nucleus for Complementary and Mutualist Regimes. Theoretically, in terms of provisions for disabled persons, the services available result from a symbiosis between the Portuguese Government and associations or organizations for disabled persons.

In terms of the allocated informants, they were all in managerial roles as Directors of Services for their Division.

3.2.2 Institute of Social Security (ISS)

Initially, there was no plan to interview civil servants in this institute. However, within a preliminary interview with a gatekeeper in Social Security, it was stated that this institute plays a pivotal role in the policy process. The ISS is divided into four main areas: the National Centre for Pensions, the National Centre for Protection of

Professional Risks, the District Centres and the Central Services. This thesis focussed on the Central Services, as it was the appropriate unit for this study on the central administration. The role of the Central Services is to manage the implementation of social security regimes and social action, as well as providing technical support and coordination to the organic structure of social security (Segurança Social, 2005). Although this Institution does not define norms or make policies, it supervises and influences their implementation. Within the ISS two informants were interviewed. One of the interviewees worked on children's issues, and the other specialised in disability issues.

3.2.3 Directorate-General for Innovation and Curricular Development (DGIDC)

The DGIDC also has both a technical and a normative function within the educational domain. It provides support in the formulation of policies, mainly in the areas of innovation and curricular development, but also works with teaching aids and educational support (DIGIDC, 2005). In addition, it has the responsibility of monitoring and evaluating the implementation of educational policy. Within the DGIDC there is a Directorate for Services for Special Education and Socio-Educational Support (DSEEASE), which has five main areas of intervention:

- Prolonged Special Educational Needs, which was divided into the following domains:
 - Sensory
 - Cognitive
 - Cognitive, Motor and/or Sensory (Multi-disability)
 - Communication, Language and/or Speech
 - Emotional and Personality
 - Physical Health
 - Motor
- Intellectual Giftedness
- Early Childhood Intervention
- Transition into Work
- European Agency for the Development of Special Needs Education (DGIDC, 2005)

The Director of Services was interviewed, as she had knowledge of all the policies covered by this directorate.

3.2.4 Directorate-Regional for Education for Lisbon, (DREL)

Instead of having one Directorate-General for Education, Portugal has five decentralised Regional Directorates (DREs), which all work directly in collaboration with the Ministry of Education and the DGIDC. Only one Regional Directorate out of the five was selected to apply to my research. It is infeasible to research all five Regional Directorates within a single-authored research project of this scope. Consequently, the Directorate-Regional for Lisbon (DREL) was selected to be the focus of this study and any conclusions drawn about educational policy relate to the policies pursued in this region.

DREL has an intermediary role in the policy process. Although this Directorate does not assist in the formulation of policy, it plays a crucial role in its orientation and implementation. The DREL comprises four Directorates: Administrative and Financial Services, the Directorate for Material Resources, the Directorate for Pedagogic Services, and the Directorate for Human Resources. From these four Directorates, all of which could possibly touch upon the issue of disability and special/additional needs, I was allocated an informant from within the Directorate for Pedagogic Services. It was stated by the Head of the DREL, that no other directorate would have the experience and specialisation to answer the questions provided. Within this directorate, a specialist in special/additional needs was allocated to give the interview.

3.2.4 The National Secretariat for Integration and Rehabilitation of

Persons with Disabilities (SNRIPD)

The SNRIPD also has both a technical and a normative function, in defining national policy regarding the prevention of disability, and the habilitation, rehabilitation and participation of people with disabilities into mainstream society (SNRIPD, 2005). This secretariat not only assists in formulating policy regarding disability, but it is also holds a database on disability related issues and policies. It informs and assists policy development. The SNRIPD has fluctuated in terms of which area of the government it belongs to. At the time of the interview, it was attached to the Ministry

of Employment and Social Security. Prior to the interviews, however, there was a change in government and the new Socialist administration created a Joint Secretary of State with the additional responsibility of the area of Rehabilitation. The creation of this post strengthened the link between social security and disability, and hence with SNRIPD. Within SNRIPD, the specialist on children's issues was interviewed.

3.2.5 National Federation of Social Security Cooperatives (FENACERCI)

FENACERCI is the representative body for cooperatives providing services within the field of social security. The aim of this federation is to support associated organisations that defend the interests and rights of people with mental disabilities and their families, (FENACERCI, 2006). Although, this institution has partnerships with the Ministry of Social Security, it also places perhaps even greater emphasis on provisions regarding education. It works alongside the DGIDC, the ISS and the SNRIPD, making it the ideal organisation through which to explore the ties the state has with civil society and non-governmental organisations. The vice-president of this organisation was interviewed for the purpose of this study.

3.2.6 Portuguese Association of the Disabled (APD)

APD is an organisation run by people with disabilities for people with disabilities. It believes that people with disabilities are the most qualified people to provide insight into their own needs and interests. This organisation not only promotes the human rights of people with disabilities but also the interests of disabled people as defined by those people themselves. This is done through consultancy, as well as lobbying and awareness-raising. By interviewing representatives of this association, it provides insights into the disability movement within Portugal and the direction it is moving in. As stated above this organisation is run by people with disabilities, and the interviewee is himself a person with disabilities. This interview also provided a unique opportunity to explore the personal experiences of this interviewee as a person with disabilities in Portuguese society.

Having now introduced the various organisations from which the interviewees were sources, the following sections explore the interview structures adopted by this thesis.

3.3 Vignettes

The vignette technique is a method that can elicit perceptions, opinions, beliefs and attitudes from responses or comments to stories depicting scenarios and situations. (Barter and Renold, 1999)

Vignettes are a method of enquiry which allows us to explore sensitive issues, without having to confront them directly. As highlighted by Gould (1996) and later by Hughes and Huby (2002), the popularity of this technique extends from the drawbacks of using questionnaires when exploring areas such as those depicted above (perceptions, opinions, beliefs and attitudes), which are of central importance to the present study. Vignettes are of great benefit in qualitative terms as they explore sensitive issues in a less threatening and less personal way (Barter and Renold, 1999). As Finch (1987: 122) argues, the vignette ‘leaves space for respondents to define the situation in their own terms.’ It also allows one to explore processes associated with decision-making in a non-direct way. This technique has been chosen in order to explore personal views on the sensitivity of the term ‘disabled child’ in a non-threatening way.

There are those who view vignettes as short stories (Finch, 1987), scenarios (Hill, 1997) or narratives (Loo, 2002) with hypothetical characters (Finch, 1987), which depict concrete examples of issues being researched and elicit responses to these issues (Hill, 1997). Hazel (1995) argues that the vignette technique allows participants to gain confidence by drawing on concrete situations in the stories to formulate more abstract ideas. Presenting these stories, scenarios or narratives allows the respondents to reflect their views, without being asked directly, which can be the most effective means of eliciting responses, especially in cases of sensitive and/or controversial topics. In the case of this research project, vignettes allow one to explore the informants’ decision-making skills in action, by providing them with concrete examples of the type of policy areas they would have to deal with at work.

This approach would allow one to explore decision-making in action, rather than just discussing it abstractly through the interviews.

Barter and Renold, (1999), have highlighted the three main purposes for which vignettes are usually employed:

1. Interpretation of actions and occurrences that allows situational context to be explored and influential variables to be elucidated;
2. Clarification of individual judgments, often in relation to moral dilemmas;
3. Discussion of sensitive experiences in comparison with the 'normality' of the vignette.

All three of these areas illustrate scenarios in which a direct approach of enquiry might deter or intimidate a respondent from providing a straightforward or honest answer, as they tap into one's personal, perhaps private and sensitive beliefs. In employing a non-direct approach, the researcher may be able to explore issues specific to these areas in greater depth and invoke more insightful responses than would otherwise be possible. Barter and Renold (1999) have also suggested that vignettes are an effective 'ice-breaker', and refer to Hazel's research on young people's views in child care policy and practice. Hazel himself noted that vignettes can facilitate discussions (Hazel, 1995).

Vignettes can equally be employed in quantitative studies. However, Finch (1987) cites West (1982) in order to question the quantitative vignette technique, since it cannot go into as much depth as a qualitative approach. The set categories required for a quantitative approach might not reflect the true insights of the respondents as they are adjusting their opinions to the categories that are presented to them (Barter and Renold, 1999). A popularly documented case within the vignette literature is that of Rossi and Alves's (1978) study on fairness of earnings within the US. Faia (1979) accused this study of producing 'unrealistic results', due to the categories it employs. The set responses they offer for their informants, Faia argues, do not reflect the real world (Faia, 1979: 951-952). However, qualitative approaches to vignettes, too, have their limitations. According to Barter and Renold (1999):

Some of the major differences surrounding the use of vignettes within qualitative paradigms include: whether they are used as a self-contained method or adjunct to other research

techniques; how the story is presented; what stage in the data collection process they are introduced; and how responses are structured. (Barter and Renold, 1999: 309)

Barter and Renold elaborate the different considerations necessary when applying the vignette technique to a qualitative study. The conclusion they draw is that the adequateness of using vignettes is dependent on the methodological and theoretical framework used by the researcher. This is confirmed by Hughes (1998):

There can be little doubt that vignette based experiences are different from real life but whether this in itself makes it an unsuitable research tool depends on the rationale for using it. (Hughes, 1998: 384)

Barter and Renold (1999) have identified three main areas in the vignette paradigm that require careful consideration. These are:

- The tapping of general attitudes and beliefs
 - Asking questions about the vignette
 - The significance of context
- (Barter and Renold, 1999: 309)

One must recognize the importance of boundaries in the application of vignettes, and hence the significance of context. Does it really depict the complexity of the real world? Hughes (1998) states:

we do not know enough about the relationship between vignette and real life responses to be able to draw any parallels between the two. (Hughes, 1998: 384)

With carefully planned vignettes one can elicit responses, thought processes and actions that can relate to everyday life. Although vignettes can provide a fictional scenario, the approaches one takes to them is similar to that which one would take to a real life scenario. This thesis intended to explore thought-processes and decisions made that are associated with actual policies regarding children with disabilities. By adopting the vignette technique, it was possible to explore how each interviewee perceived, conceptualised and dealt with a particular policy area represented within the vignette they were given.

However, this technique is often used in association with other data collection methods. Hughes, for example, recognized the benefits of integrating vignettes with other research methods in order to create a 'more balanced picture' of ones research subject (Hughes, 1998: 384). Similarly, Barter and Renold, in particular, adopted vignettes alongside semi-structured interviews:

Ultimately no research tool can completely capture the complexity of social existence; however, by adopting a multi-method approach, researchers can build on the individual strengths of different techniques. (Barter and Renold, 1999: 312)

This thesis also intends on adopting a multi-method approach in order to capture the complexity of the theories adopted above. It has adopted vignettes not only as an ice-breaker but also as a perspective by which one can explore the self. The following section presents the vignette that is used in this study.

3.3.1 Applying Vignettes to the Current Research Project

As highlighted above, vignettes have been noted by many as an effective research technique, especially in terms of tapping into personal beliefs and attitudes, as well as approaching sensitive subjects. This mode of research allows us to explore such issues in a non-direct way, through the use of stories, narratives and hypothetical scenarios. Although criticized for their alleged inability to accurately depict the real world in all its complexities, vignettes are seen to be an effective research tool when complemented by other modes of research, (Barter and Renold, 1999).

Vignettes are employed in the interviews conducted in order to tap into the interviewees' general attitudes and beliefs on disability and childhood. They are used as an 'ice-breaker' at the beginning of the interview. The themes and concepts which emerge from the vignette are then further explored throughout the remainder of the interviews.

In constructing the vignettes, it was decided to present a narrative account of a scenario highlighting many of the issues confronted by children with disabilities and their families. As elaborated above, through the selected vignettes, it was intended that this vignette would uncover general attitudes, beliefs and conceptions

surrounding the term ‘children with disabilities’ and the related policy approaches to this group. Hence, the vignette focuses on the different perceptions surrounding children with disabilities and policies regarding their welfare. As a result, I chose to use a true story that depicts real life examples of issues encountered by a Portuguese family. The selected account highlights needs that are not being addressed, that could potentially fall under the policy umbrella. This account aimed at viewing what issues the interviewees identified and also what solutions they provided. This allows one to view whether the responses provided by the vignettes correlate with the policy approaches that are highlighted within the remaining part of the interviews. The vignette selected is as follows:

João is 10 years-old. His father passed away, leaving him in his mother’s care. He has downs syndrome and is on the autistic spectrum. He attends a special school, from 9-5, during term time. As he is getting older his mother is finding it harder to care for him. The school he attends offers no extra-curricular activities, where João’s mother has to collect him promptly at 5 o’clock. Furthermore, the school offers no holiday activities, leaving his mother fully responsible for his care over these periods. His mother has applied for a place within NGOs which offer extracurricular activities, but they are fully booked. In addition, she has applied for support, such as a care assistant, but no staff is available to aid her. The only benefits she receives from the State are family and disability benefits, as well as discounts on commodities such as nappies. In this, João’s mother has to leave work early to collect him, as there is no school transport service. Furthermore she places him in day care on holidays, (when she is not on holiday herself), with no financial support from the State for these costs. The school has recommended that João boards with them throughout the week, although he cannot stay on weekends and holidays. João himself is very attached to his mother and boarding at the school would cause him great distress.

This story was presented in Portuguese to the all the interviewees within the civil service. Respondents were asked two main questions:

- How do you feel about this story and its characters?
- What would you suggest to ameliorate this situation?

The collected responses were then analysed using Sim *et al.*’s (1998) ‘locus of control,’ (which is discussed in more detail below), and were compared to the responses elicited in the interviews and the documentary data collected. The following two sections highlight the approaches taken to the interviews and documentary data.

3.4 Semi-Structured Interviews

At the root of in-depth interviewing is an interest in understanding the experience of other people and the meaning they make of that experience. (Siedman, 1998: 3)

One of the most popular forms of qualitative research are interviews, which explore specific phenomena through the use of dialogue. Whilst exhibiting some similarities with quantitative methods such as questionnaires and surveys, semi-structured interviews allow respondents the flexibility to come up with their own accounts and responses to questions in as much detail as they deem necessary, rather than requiring them to choose from a selection of set answers and limiting the space available to portray their beliefs or feelings. As elaborated by Arksey and Knight (1999), the benefits of conducting interviews include:

- The possibility of exploring the stories and perspectives of informants, especially through open-ended questions.
- Allowing nuances to be captured, through a researcher-informant dialogue, and for questions to be clarified and adapted, and new ones to be improvised
- Being sensitive to informants, which allows the interviewer to find out about the individual's characteristics and particularities. (Arksey and Knight, 1999: 34)

Through interviews, one can capture a number of factors, such as an in depth understanding of behaviours (Siedman, 1998). Interviews also allow the researcher to gain an insight into experiences, events, cultures, and processes experienced at an individual level (Rubin and Rubin, 1995). Whilst it is not feasible to cover large proportions of the population with qualitative interviews, as quantitative measures such as surveys and questionnaires are able to, interviews do allow an in depth exploration and understanding of the factors which lay behind the conditions and trends revealed by quantitative methods. As Kvale (1996) argues:

The purpose of the qualitative research interview treated here is to obtain descriptions of the lived world of the interviewees with respect to interpretations of the meaning of the described phenomenon. (Kvale, 1996: 30)

In the context of this study, interviews are the most appropriate approach to adopt, since the phenomenon to be explored is the social policy-process within Portugal

regarding children with disabilities. This method will allow the interviewer to explore how the interviewees conceptualise children with disabilities, and how they interpret their needs and policies orientated at them, by asking the interviewees directly and exploring their perceptions with them.

Rubin and Rubin (1995) highlight two models of interviewing: the tree-and-branch model and the river-and-channel model. The tree-and-branch model sees the interview having a core topic or 'trunk' in their metaphor, and main questions that extend from the trunk like branches. As Rubin and Rubin (1995: 159) argue '[t]he goal is to learn about the individual branches that frame the entire tree but still obtain depth and detail.' The river-and-channel model, in contrast, depicts issues explored within interviews as a river of many currents, where one selects a current, (or issue), and follows it through with questions that may emerge and follow on from each other. This research intends to adopt the tree-and-branch model, because in this particular study has set specific areas within a particular issue it wishes to explore rather than what may emerge from that particular issue.

This research aims at exploring how social policy is framed, within the Portuguese government regarding disabled children. It takes a social psychological approach to policy and views it as a decision-making process and aims at better understanding how key decision-makers within the government formulate decisions and, hence, policy. As discussed in the previous chapter, decisions in the policy process are a product of several inter-related factors such as job description and fulfilling job requirements; prioritisation within the workplace; the availability and management of resource; the knowledge and expertise of a particular individual on a specific issue. The interplay of these factors with each other leads to the eventual formation of a decision. The interview questions were constructed on the basis of this understanding of the policy making process.

Rubin and Rubin (1995) further distinguish between three types of qualitative questions: main questions, probes and follow-up questions. Main questions are prepared before the interview by the researcher, and provide the skeletal structure of

the interview in terms of the themes and issues to be pursued throughout the interview. Within the actual interview, they argue, probes are used in order to pursue or clarify certain issues and to encourage the informant to provide an additional response to questions which the interviewer feels need further specification or clarification. Follow-up questions, meanwhile, are used to explore any issues that may arise during the course of the interview in informants' responses, as well as the central themes, ideas or concepts under examination.

Arskey (1999) has delineated two types of questions present within an interview: open and closed questions. Closed questions are those which require only a brief predefined answer and, as such, are easier to code than open questions. However, as they limit the responses available to interviewees, they are more restrictive as a result of being pre-coded. Open questions, by contrast, are 'designed more as a trigger to stimulate the informant into talking freely about the particular area under discussion' (Arksey and Knight, 1999: 92). Hence the researcher is able to explore issues to the depth he/her deems necessary. In opting for the tree-and-branch model, this study has already provided a core structure to my interviews, establishing the areas it wishes to research within that context. It was felt that within this research project it was best to adopt a fusion between open and closed questions. Having established the structure for my interviews (tree-and-branch), open questions would then allow the flexibility to explore the areas within these parameters.

The following section will examine the set questions asked within the interviews following the discussion of the vignettes.

3.4.1 Interview Questions

1. How is disability categorised?

Hill and Bramley (1990) outline that policies are specific to a given situation. Similarly, Bolderson and Mabbett (1991) state that:

social policy allocates, distributes and delivers benefits and services to households and individuals on the basis of need which people are deemed to have by virtue of belonging to a category. (Bolderson and Mabbett, 1991: 15)

Provisions are made on the basis of belonging to a category. ‘Social aid for the needy was designed to provide exactly what work provided for the abled-bodied themselves (physical subsistence) and society (productivity) (Stone, 1984: 55). Hill and Bramley (1986), however, speculate that these same categories and their guidelines or definitions can be quite limiting, as they may overlook certain principles that need and/or could be achieved.

This question allows us to explore some fundamental principles regarding this research project. Since most of the interviewees do not have a disability and are not children, they do not share an identity with children with disabilities. As a result, this question allows one to explore how each interviewee identifies and relates with children with disabilities and how they reflect their own identity upon them in interpreting who they are and what their needs are. As highlighted in Chapter 2 there are various ways in which one can view disability, and these views can result in differing approaches to policy and the direction it takes. This question allows one to review how children with disabilities are defined by policy-makers, in order to understand at whom policies are directed and how they are structured.

2. What is your job description? What do you do?

One’s job description or the perception of one’s professional role can influence the way one makes decisions. I have elaborated some of Drake’s (1999) and Lipsky’s (1980) arguments, on the implications of one’s job and how it impacts on decisions. Drake (1999) hypothesised that civil servants take an approach to policy making related more with their professional identity and expediency. Hence, what they think their job is or should be and what they want to get out of it and works in their favour. In exploring interviewees’ job descriptions, as well as how their job is perceived by them, one can understand the context in which policy decisions are made. The main areas of exploration within this question are:

- Job competencies
- Political power
- Flexibility to make independent decisions
- Methodology of implementing policies
- Structure and network

‘Job competencies’ involve both the official job description and how the informant views his/her job. ‘Political power’ and the ‘ability to make decisions’ refer to the amount of power one has to produce an outcome, as well as the space one has to exercise this power autonomously. ‘Methodology of implementing policies’ is the process by which one exercises a decision and, hence, produces a specific outcome as a result of this. ‘Structure and network’ cover the structural setting in which decisions are produced and the networking with other organisations or personnel that are required to produce such an outcome. This exploration allows one to build up a picture of an interviewee’s professional identity, as the interviewee’s responses not only categorise him/herself, but also the associated roles they adopt within the workplace.

3. What policy areas are prioritised within your job, and in particular, what are the existing policies regarding children with disabilities?

Policy regarding children with disabilities is one of many policy areas covered by the civil service. Different departments have different priorities and thus focus on different policy areas. This question aims to explore the different areas that are prioritised by each of the organisations examined in this project and the extent to which children with disabilities prioritised. Where children with disabilities are found to be prioritised by a particular organisation, the question is then in what context they are prioritised. The main areas of exploration within this section are as follows:

- Types of provisions

- Categorisation
- Issues and areas covered
- Structure

In this context, all the prioritised policy areas were explored. The aim is to discover what categorisation used within this realm, i.e. who is receiving what, and how they fall into each category. Similarly, what areas and issues are covered within these prioritised policy areas and to what extent, and what structures, normative frameworks and procedures are associated with these policy areas? This question allows one to explore what areas the interviewees prioritise and what has influenced their decision to prioritise the things they do. It also allows one to explore which policy areas an interviewee identifies with most.

4. What are the resources available and how are they distributed?

In line with the previous question on prioritisation, this question explores the allocation and distribution of resources. It particularly focused on how resources are allocated to disabled children and in what form, e.g. cash benefits, technical aids and materials, types of support, and so forth.

5. What knowledge is there within each unit, involving key issues, and what are the existing structures in place for dealing with these issues?

There are further issues to contemplate when considering how policy is structured and what provisions are made for disabled children. Within each department there are a set structures, understandings and procedures regarding policy practice with regard to children with disability. The areas to be explored within this question are as follows:

- Policy areas regarding children with disabilities
- Associated structures for decision making and implementation
- The perceived needs and rights of children with disabilities

- Existing legislation and policy

In looking at the areas covered specific to disabled children, this question explores provisions, support, aids and benefits regarding children with disabilities. In exploring the structure within each unit from which participants were interviewed, this question looks at policy issues directed at or of interest to children with disabilities. This question not only explores this issue with reference to the responses elicited by the interviews, but also by the existing legislation and policy documentation. Within the context of the interviews, this question also allow one to explore how the participants reflect their own identity onto the approaches they take to policies regarding children with disabilities.

6. How are new issues and concepts understood and dealt with?

Policy is not stagnant. It changes over time and develops. This can be due to a variety of factors and circumstances from a changing population, demographics and society, to a change in government. In addition, Portugal, being part of the EU and a signatory in various international agreements, is also bound to the various developments within these broader international contexts. As a result, new information and initiatives are constantly being developed and pass through the various departments and institutions studied here. Within this section the following areas are explored:

- Recent new developments in the social, political and international spheres
- Main bodies and inputs influencing decision making in each unit

This question aims to explore what the main influences are on the individual participant and her/his department. In addition, it plans to explore any new developments, that are influencing the way in which conceives of their role and that of their department. Consequently, this question allows one to view who the

participant identifies with, out with the immediate surrounding of the workplace, and by whom they are most influenced.

7. How are decisions reached?

This last question aims to explore how all the factors examined above come together to form a decision. It explores the procedures, struggles, and thought processes that form the links in the policy chain and go into a final policy decision.

It has been argued that within the Portuguese State Administration there are shortcomings in terms of the communication between the different tiers of government. Thus, this question explores this aspect of the civil service, and looks at what information and decisions have an input into of those decisions taken by the particular unit that a civil servant finds him/herself in and, moreover, what information emanates in turn from that unit. The focus is also on the processes through which information is gathered by or arrives in the unit in question and how information about their activities is in turn disseminated by that department. It also explores who the decisions are orientated at, hence, who is the recipient of the outputs and decisions made. This question looks equally into the decision-making process, and brings together elements of decision making that have been discussed in the previous questions.

3.5 Managing the Interview and Vignette Data

All interviews and vignettes with the civil service were digitally audio-recorded onto an MP3 file since these interviews were conducted in the interviewees' offices. The interviews with FENACERCI and APD were recorded on tape as they were conducted over the phone and there was no means available at the time of interview to record these digitally. Unfortunately, it was not possible to conduct face to face interviews because the two interviewees in question were unavailable during the period of data collection in Portugal. However, conducting the interviews later in the research project did allow the interview data from the civil service to be analysed and processed in advance of these interviews, in order to better comprehend what areas

needed to be further explored in the remaining sessions. The taped interviews were then converted to MP3 format and subsequently analysed.

3.6 Documentary Data

In addition to the interviews, it was decided to analyse documentary data to provide an additional source of information about the legislative context in which the decision makers interviewed are operative. Various interviewees referred to specific policies or policy areas that have written legislation and documents attached to them. These documents can be divided into four different categories:

- **International Guidelines** – Ranging from UN Conventions to EU treaties and agreements.
- **Governmental Documents**
 - **Program of the Government (PG)** – The PG is the governmental manifesto. Every time a political party is elected they present a PG which sets out the plans they have for their term in government.
 - **Great Options of the Plan (GOP)** – Every year the government produces a GOP with the social and economic policy plans for the year. These plans define the structure and direct national policies shall take.
- **Legislation** – Written policies are usually published as legislation. These pieces of legislation are usually published in the Diary of the Republic. Once published they become law.

The international guidelines that are reviewed are those explicitly referred to by the interviewees. It was decided to first analyse the international guidelines, as the international guidelines influence both governmental policy plans and national legislation.

The study then proceeds to analyse governmental policy plans, which in turn influence national legislation. This is not a longitudinal study and, instead, aims to explore the policies in place around the interview period and those that have

influenced the interviewees in their recent work. As a result, this research focuses on existing policies and policy changes occurring in the period between January 2002 and 2005, which coincides with the period leading up to the interviews conducted with civil servants, between September 2005 and January 2006.

In addition, this research also explores national legislation. The focus is not only on particular policies and pieces of legislation mentioned within the interviews, but also the policy guidelines associated with those policy areas mentioned. The following section shall highlight how the data collected from the vignettes, the interviews and the documentary data were analysed.

3.7 Ethics

This thesis followed the guidelines of Edinburgh University's Research Ethics Framework. This study did not tackle intimate, personal nor private issues, and therefore did not have to tackle serious ethical considerations. Nonetheless, in addition to the university's guidelines for good practice it also took into account the ethical considerations of the interviewees and their institutions.

The main ethical consideration of this study was with regard consent. In order to interview the informants within Social Security and SNRIPD, permission was requested and granted by the Joint Secretary of State for Social Security and Rehabilitation. In addition, with regard to interviews within the Ministry of Education, clearance was needed from the National Commission for Data Protection (CNPd), which duly gave its consent for the interviews to go ahead. In terms of the private institutions, permission was granted by their boards of directors. In additional permission was granted by all supervisors and/or line managers of the interviewees.

Before the interviews the informants were sent a synopsis of the research project and its principal aims and objectives. This was also sent to the Secretary of State and the head of the CNPD. Each informant was also given a copy of the main interview questions listed above. Only the vignette was not sent beforehand, but the informants were aware that it would be part of the interview. Within the interviews the

informants were given the option of anonymity and asked for consent for the interview to be audio-recorded. Most did not request anonymity, but preferred not to be mentioned by name in the text. All agreed to being recorded and for the recorded data to be kept private. Furthermore, it was agreed that once the thesis was ready, each interviewee would be sent a copy via email.

3.8 Data Analysis

The aim of this thesis is to explore how key decision-makers within the Portuguese civil service formulate policy-based decisions regarding the welfare of children with disabilities. This question can be broken down into three main focal points of analysis: written policy, decision-maker, and children with disabilities. The following two sections elaborate how these two focal points are explored and analysed in this thesis through the use of thematic coding.

3.8.1 Transcription and Translation

All the interviews and the majority of data collected in the course of this project were in Portuguese. As a result, all interview data had to be transcribed and, in turn, all data in Portuguese had to be translated into English for inclusion in the final thesis. Given the large quantity of data collected, only the data relevant to the study was transcribed. Similarly, only those sections of the data quoted directly in the text were translated into English. Since no financial assistance was available for transcription and this was a single authored project, it was felt that a full transcription of all the interview data would be too time consuming. The judgement was also made that this was unnecessary as some parts of the interviews were irrelevant to the central focus of the project.

Many scholars have discussed the impact that translation has on data analysis and interpretation. Vulliamy (1990) discussed that the main influential factors in research that data is translated by the researcher is:

- their autobiography
- their understanding of the language and culture being studied.

In the case of this research, the researcher-translator is of Portuguese origin and lived in Portugal for the first eighteen years of her life. However, having attended an English language school from the ages of 3 to 18, the researcher is fully bilingual (English-Portuguese) and, as a result of her upbringing, has an insider knowledge of Portugal and Portuguese culture. Birbili (2000) argues that being an outsider and researcher-translator may lead to one missing the significance and weighting of certain words within the culture being researched. As she verifies, this symbiosis in language and cultural understanding is widely supported in the literature as the optimal approach to research in a different language or country. However, although this approach is optimal, there are still difficulties in translating data.

The main problem with translation is that languages are grammatically and lexically different and thus some words and phrases may exist in one language and not in the other. This can result in certain elements being lost in translation (Birrili, 2000). In order to tackle this problem, all questions asked within the interviews were broken down and redressed in order to gain a comprehensive understanding of what the interviewees meant. They were also asked to clarify any concepts and assertions they introduced when answering questions. One or two interviewees were contacted again after the interview in order to clarify certain responses, which appeared ambiguous when analysed subsequently.

In terms of the documentary data ‘back translation’ was adopted in situations where the meaning of the text was unclear or that needed further clarification. Back translation refers to the following process:

- a) the translation of items from the source language to the target language
 - b) independent translation of these back into the source language
 - c) the comparison of the two versions of items in the source language until ambiguities or discrepancies in meaning are clarified or removed
- (Birrili, 2000; Ercikan, 1998:545; Warwick and Osherson, 1973:30)

Other similar documents and interview data were used wherever possible in order to clarify meaning or certain words or phrases which were unclear. In addition, various dictionaries (Reverso 2009, Priberam 2009 and Porto Editora 1995) were used in order to support the translation process.

3.8.2 The Decision-Maker

Within this research, the decision-maker is one of many entities that put policy into practice. They define the direction policy takes. In order to analyse the decision-maker this study chose to explore her/his identity in the context of policy decision-making. This was done by exploring self-categorisation and role-identification.

Through the use of thematic coding, this thesis attempts to primarily review the interview data in the context of the decision-maker and code the data into two areas: self attributed categories and roles. Within categories, this thesis explores any adjectives and/or nouns the interviewees use to define themselves. The analysis of roles looks at what actions the interviewees describe themselves performing. Together, this information will be used to construct the professional identity of the decision-makers and used in turn to explain the structure they give to policy.

In addition, this thesis also examines how the interviewees identify and categorise others, with particular regard to children with disabilities. This will be discussed in the following section.

3.8.3 Children with disabilities

In order to fully answer the question this thesis poses, one also needs to explore the understanding and approaches there are within policy and practice, regarding children with disabilities. As previously discussed, there are various ways of viewing and identifying children with disabilities. As a result, this category is analysed in the context of the theories introduced above. These are divided into two sections: the medical model vs. social model, and the structural/spatial model.

3.8.3.1 The Medical Model vs. Social Model

There are various ways in which one can view the interplay between these two models. First and foremost, one can explore how one views disability. Is it the result of impairment or social oppression? Secondly, there is the context in which provisions are given. Are they aimed at ‘normalising’ the individual, hence adapting her/him to their surroundings, or are they aimed at adapting the social setting and physical surroundings to the individual. All the data collected is analysed with these themes in mind.

Firstly, this study aims to evaluate how written policy and the decision-makers define disability. Do they have a medical or a social understanding of disability? Secondly, this study will explore the approaches that policy has to provisions. Hence, it explores whether provisions made are aimed at normalisation of the individual or a change in the social environment. This thematic coding is also be applied to the documentary data, as well as the interview/vignette data.

However, the interplay between the medical and social model can be far more complex than a simple division of perceptions into whether disability is exclusively medical or social, especially when taking childhood into account. As stated by Hill and Tisdall (1997), children have various social layers surrounding them affecting how policy is administered and in what context. This is why this study has also introduced a structural model to address these issues.

3.8.3.2 The Structural/Spatial Model

I propose a structural model, which I would like to apply to the data analysis. Sim *et al.* (1998) conducted a study on whether disabled persons and care professionals could agree on defining needs. They based their research on issues that refer to the Community Care Act (HMSO 1990), in which their criteria was structured around the Individual/Social model of disability.

As highlighted above within their study, the following diagram was presented:

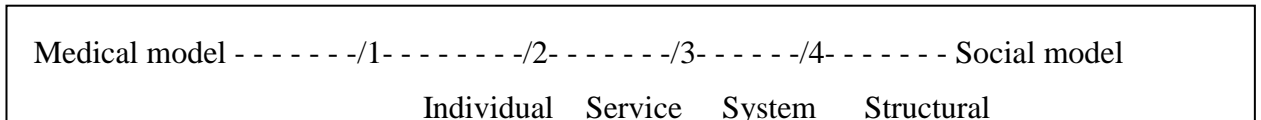


FIG. 1. Locus of control model (Sim *et al.*, 1998: 60)

The categories of this 4-point scale are defined below:

Individual: this refers to an approach where the focus for change is targeted at the individual; services are discrete and tailored to personal circumstances. This most closely corresponds to the medical model.

Service: here the emphasis for change is aimed at improving service delivery on a specifically local level.

System: in this the locus of control is centered on the management and coordination of the wider framework in which local services are set.

Structural: the focus for alteration is identified as the broader social, legislative or economic context within which the health and welfare system are based. This most closely associates with the social model in which handicap is perceived as originating from disabling social policies rather than from physical impairment. (Sim *et al.*, 1998: 61)

This scale or rather ‘locus of control’ deconstructs the social/medical model into different stages, hence illustrating a gentle transition from the individual/medical model to the social model of disability. It starts with the individual stage, where change is centred on the individual, and services are aimed at catering for impairments, which are viewed as the source of disability. The service stage, externalizes the individual stage in that it focuses on the services directed at the individual. At the system stage, change is centred on the coordination and management of the services directed at the individual, whereas the structural stage takes the system stage to a more abstract level that is based on rules, policies and systems, making disability a socially constructed phenomenon.

In light of this scale, it is important to note that, although my research focuses on the ‘Structural’ or perhaps even ‘System’ side of the spectrum, I wish to explore whether the attitudes and beliefs of decision-makers fall into that same spectrum. As a result, I bring in Sim *et al.*’s deconstruction of the individual/social model into six working categories, to explore the decision-makers’ views. These are as follows:

Self: in which people fail to perceive an external fault and blame themselves.

Self-Micro: refers to the externalization of problems to (1) the relationship held by the individual with the local social services and (2) the physical environment.

Micro: refers to the identification of service problems at a local level, and (1) the relationship between local services and local user groups and (2) the inter-relationship between caring agencies.

Self-Macro: refers to the identification by an individual 'consumer' of the problem as arising from limited choice or poor quality or delivery of service at a structural level.

Micro-Macro: refers to (1) the identification by disabled people of their problems as stemming from a structural level and (2) to their collective awareness of a disvalued status, and therefore to the relationship of user groups with the social and environmental structure.

Macro: refers to the general identification of problems as stemming from a structural level. (Sim *et al.*, 1998: 61)

Given the nature of Sim *et al.*'s study, it is understandable to see a slightly more consumerist slant to their categories. They are also specific to the disabled person's interaction with society and the state. These categories fall short in one element. In terms of disabled persons and even children, the links between the self on the one hand and the micro (services available to the individual) and/or macro levels (the structure or system in which the services are held in) on the other hand, are not as clear cut as depicted above. These categories fail to consider the implications of the family and when considering the Portuguese welfare state, it is important to bring in the family element.

As previously suggested, children live seemingly distinct parallel lives to that of adults. They are seen as separate from the adult world and unable to participate fully and individually in the 'adult world' of politics. It could be argued that with the new age of children's rights and international conventions such as that of the 'UN Convention on the Rights of the Child' there has been a shift in the participation of children in the law and in politics to a more active role. But to what extent does this apparent shift have an impact on social policy? What impact has this shift had on children with disabilities?

It is noted in the Portuguese Constitution that the state 'shall ensure that [disabled citizens] enjoy their rights to the full extent subject to the rights and duties of their parents or guardians' (Portuguese Constitution, 1997, article 71. 2 – Disabled Citizens). Given the prominent role afforded in the constitution to parents and

guardians, one of my principle questions here is whether policy is orientated at and structured for the child themselves or the family? The answer to this question is essential in exploring the attitudes and beliefs surrounding childhood and furthermore disability, especially in terms of notions such as dependency and ‘second-class’ citizenship. Furthermore, the child with disabilities is an individual in their own right. By viewing the child as part of a family unit and overlooking the relationship between the child and the family, or even the family and the State, one risks undermining the child’s rights, since in this case it is subject to the parents’ rights. As a result, it is important to incorporate family and/or guardianship into the categories above. As a result I propose the following:

Self: in which people fail to perceive an external fault and blame themselves.

Self-Familial: refers the externalization of problems to the relationship held by the individual with the family and/or guardians.

Familial: in which the family and/or guardian fail to perceive an external fault and blame themselves, and take full responsibility for the disabled individual and are the individual’s main decision-makers.

Self-Micro: refers to the externalization of problems to (1) the relationship held by the individual with the local social services and (2) the physical environment.

Familial-Micro: refers to the externalization of problems to (1) the relationship held by the family and/or guardians with the local social services and (2) the physical environment.

Micro: refers to the identification of service problems at a local level, and (1) the relationship between local services and local user groups and (2) the inter-relationship between caring agencies.

Self-Macro: refers to the identification by an individual ‘consumer’ of the problem as arising from limited choice or poor quality or delivery of service at a structural level.

Familial-Macro: refers to the identification by a ‘consumer,’ within the family and/or guardian sphere, of the problem as arising from limited choice or poor quality or delivery of service at a structural level.

Micro-Macro: refers to (1) the identification by disabled people of their problems as stemming from a structural level and (2) to their collective awareness of a disvalued status, and therefore to the relationship of user groups with the social and environmental structure.

Macro: refers to the general identification of problems as stemming from a structural level.

(Adapted from Sim *et al.*, 1998: 61)

This categorisation, applied to the present study, depicts different levels which one can view as disabling factors or levels of disablement. Starting with the ‘self’ or individual, taking the medical model approach, where disability is the liability of the individual. The familial category has been introduced, which looks at the disabled individual as being the liability of the family. The rationale behind this category is that, if the family and/or guardians have full responsibility and are the main decision-makers as regards the child, then the family’s decisions may too have an impact on

the child's life and level of disability, and may be held accountable for this. The micro level, as elaborated above, refers to the local services and physical settings that cater for the disabled individual, making them liable for affecting or adding to disability. Furthermore, categories linking the self/familial to the micro level manifest disablement through the relationship of the individual or his/her family respectively, with local services and the physical settings. The macro category looks at the environmental and social structure, as well as, the structure of the system incorporating the services. As a result, a new 'locus of control' is developed, producing a new adaptation of Sim *et al.*'s:

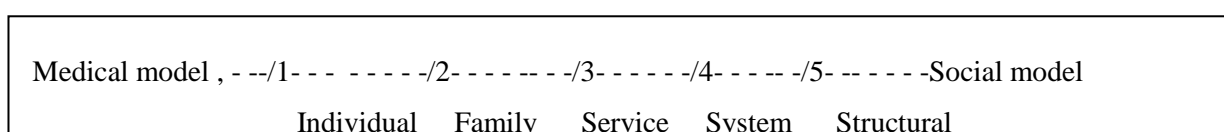


FIG.2. Enhanced Locus of Control Model (adapted from Sim *et al.*, 1998:60)

As a result, this locus of control model was applied to the data collected regarding disability-related issues, especially in the context of vignettes section of the interviews. It was used to assess the level at which needs and rights are being addressed, and in what context children with disabilities are being identified.

3.9 Concluding Remarks

This thesis aims to explore decision-making regarding children with disabilities in the Portuguese civil service. To answer this question this study employs a multi-method qualitative approach, combining 3 research methods: interviews, vignettes and qualitative content analysis.

Interviews allow the researcher to undertake an in depth exploration of events and processes. Although when compared to quantitative measures, interviews are harder to code and can only cover small amounts of the population, this method allows the researcher to gain a deeper understanding of belief systems and thought processes, which cannot be depicted in adequate depth via the use of research methods such as

surveys. In the case of this research project, interviews allowed me to engage in the policy process and to understand what led a key policy decision-maker to reach a decision. By adopting the tree-and-branch model, the parameters of the interviews were to avoid becoming sidetracks and to remain focused on the information of principal importance to the main research questions

The interviews were initiated via the use of vignettes. Vignettes have been noted by many as an effective research technique, especially in terms of tapping into personal beliefs and attitudes, as well as, approaching sensitive subjects. This mode of research allows us to explore such issues in a non-direct way, through the use of stories, narratives and hypothetical scenarios. Although criticized in terms of their ability to depict the real world in all its complexities, it has been seen to be an effective research tool when complemented by other modes of research. This method has been selected as it allows me to avoid a perceived threat of being interrogated by offering a non-threatening task, hopefully establishing a relationship of comfort and trust with the informant at the beginning of the interview. Vignettes were also used to explore innate perceptions of the term ‘children with disabilities.’

In addition, qualitative content analysis of documentary data was adopted in order to view the policy structures in which each decision-maker operates. By reviewing the written policies and guidelines, one can view not only the basis of the policy on which decisions are made, but also the influence they have on the decision-maker themselves. These documents included international guidelines, party manifestos, policy plans and legislation. This analysis was used not only to support the interview/vignette data but also to add to the understanding of the policy process that emerges from them.

This study comprises 10 interviews in total, 8 with civil servants and 2 private sector employees. In the case of the civil service in particular, these 10 people are the key people to talk to regarding policies orientated at children with disabilities. Although the quality of interview/vignette data was very rich, this thesis benefited tremendously from the qualitative content analysis of policy documents. This

triangulation allowed this research to explore the decision-maker in the context of the policies that surround her/him. It also provided a sounder structure to this thesis, incorporating all-inclusive results.

This study aims at exploring how key decision-makers formulate policy decisions that regard children with disabilities. Although, this question incorporates 3 areas (decision-makers, policy and children with disabilities), there are two analytical focal points within this thesis: the decision-maker and children with disabilities. This study takes a social psychological approach to policy, as it is interested in how identity impacts on key actors' decision-making regarding children with disabilities. Policy is the context in which this interplay occurs. As a result, the main focal points are decision-makers and children with disabilities. In terms of the decision-maker it took the combination of self-categorisation and role-identification from SIT and IT, and thematically coded the data accordingly. In terms of children with disabilities, not only was the divide between the medical and individual model explored within the data but also the divide which emerged from a structural/spatial point of view. I believe that the combination of the different theories highlighted within this and the previous chapters, provides an effective analytical tool for the data, and hence, effectively answers the question this thesis poses.

4. Identifying the Context of Policy Decision-Making: International Guidelines

4.1 Introduction

One of the main influences on policy decision-making that arose during the course of the research project, were written guidelines. They form the basis on which decisions are made, and the parameters in which decision makers operate and of the roles these professionals identify with in the policy decision-making context. Within the interviews, it transpired that the influences on the policy process can be broken down into 3 areas: international guidelines, governmental plans and national legislation. Each of these areas will be covered in the present chapter and the following two chapters. They will each be explored in connection with policies regarding children with disabilities. Above all, these chapters will examine those areas identified as being of particular importance in the interviews conducted.

This chapter focuses on international guidelines. The informant for International Relations (IR) highlighted implementation reports and international guidelines as the main documents of importance in her job. As part of her technical/normative role, she disseminates information about international guidelines and uses them in structuring national legislation. However, she was not the only person to highlight the importance of the above documents in their role. The informant for Special Needs Education (SNE) was also keen to mention her involvement with European and International Organisations, as were most of the other senior-level civil servants that were interviewed. In all these cases, International guidelines played a key role in forming the professional identity of the respondents in question.

The aim of this chapter is to view how children with disabilities are identified and conceptualised within international guidelines, and explore how these guidelines may affect policy structures in which each of the interviewees operates. The volume of international guidelines in force were not as substantive as either of the other two sets of documents analysed, the Governmental plans and national legislation, but those which exist are equally as important and influential (if not more important) than the other two. The guidelines mentioned are those that were identified in the

interviews as being the most influential at that time. In the following section I will set out which documents and international agreements were highlighted within the interviews and assess their significance for the formation of policies towards disabled children in Portugal.

4.2 International Guidelines

Within the interviews the informant for SNE mentioned various international guidelines that she looks to and works with when formulating policy:

So we use the guidelines we know from the system and international guidelines. So we have European guidelines and the guidelines outside of Europe. We also look to EURYDICE. I also work in the European Agency [for Development in Special Needs Education] and that compilation of data helps us come to a decision. And then we take into account everything that is international. About Standard Rules for Equalisation of Opportunities, the stuff from UNESCO, and now the ICF; the classification of functionality from the WHO. So we always have to keep an eye on international guidelines about this matter. And we try to adapt them to our country and its current situation. (informant for SNE)

Throughout the interviews, various informants discussed the introduction of International Classification for Functioning, Disability and Health (ICF, or CIF in Portuguese) produced by the WHO and the guidelines it sets out for the classification of disability. In fact it was a principal tool used in the Portuguese context for classifying and perceiving disability. If one looks on the WHO's website, it lists 'Disability and Rehabilitation' (DAR) as the only subject in its section on 'Programmes and Projects'. Furthermore, given the way in which the ICF is structured, especially when one looks at their checklist, it is clear that rehabilitation is the main form of provision advocated by this organisation. There is a heavy emphasis on body function and activity and, although there is a section on activity and participation (and even on environmental factors), all provisions pertain to the functionality and the limits on functionality of the body. When seen in this context, the importance given to rehabilitation in Portugal can perhaps be explained in terms of external influences such as the above documents rather than internal conceptions of disability and treatment. If Portugal looks to the WHO or ICF for guidance in disability policy, then this is the message they are receiving: [t]hat disability equates to rehabilitation.

Barnes (2003) stated that there are three ways in which one could interpret the relationship between disability and rehabilitation: the orthodox 'individualistic' medical definition, the liberal 'inter-relational' account, and the radical social/political interpretation (which relates to the social model of disability discussed in previous chapters). The first model refers to the traditional WHO classification of disability, which was broken down into three interdependent categories of impairment, disability and handicap. Since this classification stated that impairment resulted in one being disabled and, furthermore, handicapped, the term 'rehabilitation' concentrated on getting the most of the body and to help persons with disabilities realise their utmost potential. With the introduction of the ICF, the notion of disability slowly changed and so did the understanding of rehabilitation which followed from this, bringing us far closer to the more liberal model.

As stated by Barnes above, the ICF to a certain extent still maintains the classic three-fold system previously mentioned. Body function and structure can account for impairment and activity can equate to disability, whilst participation levels refer to handicap. The difference between the former 1980's WHO classification and the ICF is that the ICF takes into account environmental factors, synthesising the individual model with the social model. However, the success of this new classification can be limited as there are no effective tools to monitor or overcome these environmental factors, especially in the field of government and policy-making. The ICF is more socially oriented, and takes a social approach to rehabilitation by focussing more on integration and making access to rehabilitation more readily available and widespread. However, most practitioners in this field can only offer individual medicalised support. In addition, there is a risk with the ICF represents the opposite of what is occurring in society more generally in terms of the 'medicalisation' of everyday life (Barnes, 2003).

The radical socio-political approach to the relationship between disability and rehabilitation is associated with the rise of the social model of disability and its intricacies. Barnes (2003) explored the distinction between impairment and disability, and the unsuccessful attempts at separating the two concepts. As

illustrated in Chapter 2, this distinction between impairment and disability has been a source of much debate (see Crow 1996: Watson and Shakespeare, 2002). Through the emergence of the social model of disability, there has been a struggle to distinguish disability as a result of social settings and environment. However, it has been hard to separate completely social barriers from impairment, since impairment needs to be taken into account in order to remove barriers. Although the politicisation of disability has called for radical social and cultural change, disability is still seen as a health-related or ‘medical’ issue. There is emphasis on filling in the gap between disabled and able-bodied individuals and, as a result, rehabilitation is orientated at this. However, since there is a medical influence on rehabilitation, it can be seen as an antithesis of the socio-political movement. Interestingly, this is an occasion where one can see how the process of rehabilitation can influence the perception of disability rather than vice versa. This distinction will be further discussed in chapter 6.

In the Portuguese language, there is one word, ‘*deficiencia*’, that refers to both disability and impairment. Barnes (2003) mentioned the difficulty of nations worldwide to grasp the social movement is due to differences not only in terms of a country’s economy, but also differences in language. In the case of Portugal, having an all-encompassing word for disability and impairment may result in an inability to politicise disability and advocate the social model. By looking to the WHO and the ICF there is a risk of medicalising everyday life for people with disability. Similarly, including technical aids within the remit of rehabilitation legislation suggests a medical-based approach to their allocation and provision. Furthermore, measures such as the ECI and Special Education not only have a rehabilitative nature to them, but are also reliant on the measures provided by individual (and mostly medical or healthcare) professionals. These measures are not only directed at the child’s disability but at the surrounding social structures such as the family and schools. Although this suggests a more social approach to disability, the ECI is orientated at educating the family in supporting and bringing up a child with a disability, which is carried out by professionals mainly in the rehabilitation sphere. As a result, there is a risk parents, being accountable for their child’s disability, are being educated to

rehabilitate their child in such a way that will medicalise their everyday life, rather than concentrating on integrating and including their child in society. Furthermore, because these measures are available, it may result in contentment amongst parents that ‘something is being done,’ rather than a concern with whether ‘what is needed is being done.’ Similarly, schools are being allocated technical aids and support, under a rehabilitative/developmental umbrella and they too have to medicalise the child’s participation in school in order to assess what support is needed in order to support this child’s disability.

The ICF is a classic example of the differences in knowledge between top-level and lower-level civil servants. The informant for SNE was up-to-date in terms of the most recent developments and the latest terminology employed in the field of disability policy and practice, especially in the international context. She works with European agencies and is well grounded in international codes and guidelines. She is competent in the English language. The informant from DREL, by contrast, does not know English. Her job is to assess and allocate educational support and, although the guidelines she adopts may be covered by certain international guidelines, she may not be directly aware of what those guidelines are or whether they are already outdated in the international realm. It is hard to keep up to date with international guidelines if one does not know one of the main UN languages (especially English) and, as a result, one has to wait for documents to be translated. The informant for DREL did use the word ‘handicap’ on a couple of occasions within the interview. This may have been because she may have thought that ‘handicap’ was still a politically correct term and wanted to exercise her knowledge of the international terminology. This also suggests that she hasn’t kept up to date with debates about the use of disability associated language and the development of the disability model. The ICF had only recently been translated and disseminated in Portuguese, but this classification had been around for a few years, meaning that senior level civil servants would, and should, have been aware of its existence and contents. However, can one blame the informant of DREL for not being aware of the development of the disability model, or should it be the responsibility of her supervisors and their supervisors to filter through this information and train their staff? In addition, when

the informant for DREL used the word ‘handicap,’ it was because she was trying to explore the meaning of disability further, and could not find another word. This suggests that having one word incorporating the full meaning of disability can be quite limiting, especially if it means being ‘deficient’ rather than ‘disabled’ and, moreover, being ‘deficient’ rather than just having a disability. By having one all-encompassing word, it stops one from exploring this situation and its circumstances. It also does not allow for disability to be made distinct from the person. The person becomes their disability. It is their entire identity, especially in the view of others. Perhaps what is needed for Portugal, is for the term disability, and the associated language, to be re-created and re-conceptualised allowing it to meet the requirement of the current field of disability studies and to catch up with international standards and terminology. Although new innovative measures and policies may be introduced into Portuguese policy-making, the existing outdated conceptions and perceptions of disability may trump their success.

Aside from the ICF, the informant for SNE seemed to prefer discussing European guidelines and initiatives rather than international guidelines. As stated above, she works directly with the European Agency for Development in Special Needs Education (from hereon referred to as the European Agency), which could account for her stronger identification with this agency. In terms of the UN initiatives, she only mentioned UNESCO and not the UNCRC, which does mention children’s rights and superficially touches upon inclusive education. Perhaps this indicates that children with disabilities, within the sphere of education, are viewed as *people* with disabilities, rather than as children specifically. This may be primarily because the aim of special education is to ameliorate disability, making disability the main focus point. This point is emphasised by the fact that informant for SNE did mention the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (Standard Rules) instead, that focuses on the equalisation of opportunities of people with disabilities. In terms of education it states:

States should recognize the principle of equal primary, secondary and tertiary educational opportunities for children, youth and adults with disabilities, in integrated settings. They should ensure that the education of persons with disabilities is an integral part of the educational system. (Standard Rules, 2006: 6)

According to the standard rules, education of people with disabilities should be part of the education system and ideally should be provided in an integrated setting. In support of this concept, the standard rules suggested a few supportive guidelines:

- General educational authorities are responsible for the education of persons with disabilities in integrated settings.
- Education is to be provided in mainstream schools, where adequate accessibility and support services should be provided.
- Parent groups and organizations of persons with disabilities should be involved in the education process at all levels.
- In States where education is compulsory it should be provided to girls and boys with all kinds and all levels of disabilities, including the most severe.
- Special attention should be given in the following areas:
 - Very young children with disabilities;
 - Pre-school children with disabilities;
 - Adults with disabilities, particularly women.
- To accommodate educational provisions for persons with disabilities in the mainstream, States should:
 - Have a clearly stated policy, understood and accepted at the school level and by the wider community;
 - Allow for curriculum flexibility, addition and adaptation;
 - Provide for quality materials, ongoing teacher training and support teachers.
- Integrated education and community-based programmes should be seen as complementary approaches in providing cost-effective education and training for persons with disabilities.
- In situations where the general school system does not yet adequately meet the needs of all persons with disabilities, special education may be considered.
- Owing to the particular communication needs of deaf and deaf/blind persons, their education may be more suitably provided in schools for such persons or special classes and units in mainstream schools.

(adapted from Standard Rules, 2006: 6)

According to the standard rules, integrated schooling is encouraged, rather than inclusive schooling. In fact, inclusive schooling is not mentioned at all. According to Save the Children's 'Report on Inclusive Schooling' (2002), the integration can be a limiting educational measure as it adopts a 'normalisation' perspective on disability. Measures are orientated at rehabilitating the child or making her/him adapt to the schools educational measures. On the other hand, inclusion, which is the measure that Save the Children supports and advocates, is based on the social model of disability. It focuses on changing the educational environment in order to meet the child's needs. However, this is not highlighted in the standard rules above. All measures in the Portuguese context are orientated at integration, and helping the child or person fit into the set educational setting and, if they do not adapt to this environment, they can be transferred to special schools. Providing and highlighting

this option allows schools and the state to have a back out clause in shaping their provisions. More recent UN measures, the Convention on the Rights of Persons with Disabilities (UNCRPD) have started to address the issue of inclusion. In the case of Education, Article 24:2 of the UNCRPD pushes for education to be inclusive and accessible. This convention also distinguishes children with disabilities, and re-affirms their rights as children (Article 7). However, although Portugal has signed this convention, and its optional protocol, they are yet to ratify it. Once ratified, it will be interesting to view the impact of this convention on Portugal. Currently, as will be discussed below, the measures highlighted within the Standard Rules are similar to those within Portugal. This suggests that UN documents have significant influence on Portuguese policy structure. These measures advocate involving civil society or the community in educational provisions. Portugal does invest significantly in private-public partnerships. However, by advocating this approach, the standard rules are indirectly advocating that it is acceptable to let the state rely on the community to provide these measures. This could be limiting as many of the changes that are advocated in the social model of disability require a global, all-encompassing approach.

UN organisations, the Standard Rules as well as UNESCO incorporate a wide-range of initiatives and information that refers to all countries. As a result, guidelines need to appeal to a wide-range of countries with differing levels of development and welfare coverage. When accessing UNESCO's website it is the needs of developing countries that seem to be most prominent. Nonetheless, this website not only lists the ICF, but also UNESCO's own set of guidelines for special and inclusive education.

The philosophy of education that caters to the needs of all children can be said to rest on three cornerstones:

- handicap seen in relation to demands from the environment
- a holistic view of the pupil
- the principle of non-segregating measures (UNESCO, 2008)

Although they list the ICF as a useful link, it still seems to retain the terminology and stances present within the old 1980s WHO criteria. UNESCO in 1994 cooperated in the production of the Salamanca Statement that addressed the issue of special needs

education. In their mission for providing 'Education for All', this statement pushes for inclusive schooling. However, if one is to search for the Salamanca Statement on the UNESCO website, it will render 'no' or '0' results, and there was no mention of the Salamanca Statement or its goals on their website. What was listed was the above, and if one is to look at inclusion, it mentions the inclusion of marginalised or vulnerable groups and a category which children with disabilities can easily be overlooked.

As discussed above the intention is not to promote the 1980s guidelines, but rather the ICF. However, the word handicap already has a preset schema attached to it making it hard to look past it. The concept of a schema is drawn from the work of George Lakoff (2004). Lakoff highlighted the importance of certain words and their meanings, and how they can make or break political campaigns. He stated, for example, that the Republicans won the US elections by employing specially selected terminology that resonated with the electorate, something which the Democrats failed to do. These words invoked selected schemas that, in the case of Republican voters, had positive connotations associated with them, which deemed them more popular with this target audience. UNESCO's three cornerstones highlighted that 'handicap seen in relation to demands from the environment'. If we are to read handicap as 'the disadvantage the individual encounters, as a result of the impairment and/or disability, when compared with his or her peers' (WHO, 1980), it may result in disability remaining in the 1980s context and completely overriding any social context that may be intended. According to the European Agency:

From a historical perspective, the care of pupils with special educational needs has developed, in this way, from a segregated approach into a more integrative approach, with the placement of special teachers in mainstream schools. Nowadays, the Support Education Services are more and more viewed as an educational support and resource service for mainstream schools. As the Salamanca Statement establishes, special institutions are thus being transformed into specific resource centres that offer support to the educational and social community.

(European Agency, 2008)

The European Agency was set up as a platform for different European countries to collaborate with each other, and is maintained by the Ministries of Education in

different countries. In the overview of Portugal for this agency, it states that Portugal has progressed from a segregated approach to an integrative approach to education with regard to special educational needs. In addition, it refers to the Salamanca statement and states that, as a result of the latter Portugal has invested in transforming special institutions to supportive resource centres. However, the word 'inclusion' or 'inclusive' is hardly (if ever) used regarding special educational needs or mainstream schooling. This suggests that the meaning of inclusive schooling is either being lost in translation or is not being adopted at all.

Commentators such as Julie Allan (2006) have speculated that 'inclusion' is a buzz word that can be quite deceiving. Often, Allan argues, the idea of inclusion is far better than the reality of it. She suggests that the term is usually interpreted in the context of 'managing difference' (Allan, 2006: 126) and tolerating each other, which places a constant emphasis on exclusion and the difference between people with disabilities and people without disabilities. This conception, therefore, starts to sway from the inclusive environment that is being sought, and again implies a more normalised approach to disability by suggesting that people without disabilities should allow people with disabilities to be 'one of them.' In addition, the process of inclusion is being addressed at the policy/structural level and not necessarily in dialogue with children and young people and their views on what inclusion means to them. It is clear that with key terms such as 'inclusion', one needs to address and fully grasp their complexity and what they entail. This could account for Portugal overlooking the inclusive terminology highlighted in the Salamanca Statement, or could reflect a lack of knowledge of what inclusion is about. Drawing on Allan (2006), this thesis argues that concepts such as inclusion require us to reconsider and rethink our understanding and conceptualisation of disability and also, to a certain extent, our conceptualisation of ourselves.

In addition to the ICF and UNESCO, the informant for SNE also mentioned the EURYDICE and the European Agency. These agencies present a forum for different European countries to present and discuss the measures they have adopted in the field of disability and their relative success. The aim is to learn from each other and

develop best practice together. In accordance with the priorities highlighted by the informant for SNE, the European Agency's main areas of focus are inclusive education and classroom practice, ECI and the transition into employment. However, Portuguese reports to this agency are quite patchy and limited. The EURYDICE, in particular, has offered a comprehensive report on the Portuguese education system. With regard to special education it states:

Special Education is guided by the principles enshrined in legislation, which is the Education Act, Law No. 46/86, of 14th October, Decree-Law No. 35/90, 25th of January; Decree-Law No. 319/91, 23rd of August – and the underlying philosophy is based on several international resolutions such as the Salamanca Declaration for Special Education Needs.

These principles can be summarised under three fundamental rights:

- The right to education
- The right to equality
- The right to be part of society

(adapted from EURYDICE, 2006/7)

From the Portuguese report, the influence of UNESCO is clear. This is primarily because UNESCO pushes for and supports the principles highlighted above through the Salamanca Statement. Three of its main targets are participation, community and equality (UNESCO, 2008), all of which are mentioned above. However, the main influence, bearing in mind that the Portuguese report was produced in 2006, was in the following statement:

To attempt to enshrine the right, duty and responsibility of the state and civic society in dealing with persons who are handicapped and/or have special learning needs, to develop ideas and scientific and pedagogic research, at national and international level, related to special education. No less important was the contribution of reformist attitudes that brought about change to the education system from the end of the eighties and expressed in the Education Act. Also important were recommendations made by international bodies on access for handicapped pupils to the regular system of education and the experience gleaned over a number of years in which handicapped pupils have attended regular schooling. (EURYDICE, 2006/7)

Although the ICF had been disseminated at this stage, this report adopts the word handicap. Moreover, this report makes a possible distinction between people who are handicapped and people who have special learning needs. As a result, it may not be

surprising that the informant for DREL adopted the term handicap in her interview. Furthermore, this extract re-emphasises the medicalised view and approach there is to disability within education. Perhaps not only Portugal needs to reconsider its use of disability-related terminology but also the UN needs to be more consistent in its approach. However, if this is the approach to legislation, then there are other things to be considered. The following chapter shall explore legislation directed at children with disabilities within the sphere of education, and how the interviewees identify with them.

Like the informant for SNE, the informant for SA highlighted that international instruments, such as the UNCRC are taken into account in formulating policy. As stated by the informant for SA, once ratified these international agreements become the law. However, the informant for IR highlighted a few limitations in the application of these conventions.

We do not do enough to adapt the national legislation to what we ratify internationally. One of the reasons for that could be because we do not have a good articulation between ministries. We feel that a lot, especially when we are doing reports. When there is not a coordinating body for reports, which is the case of the UNCRC, there isn't a body that collects the information from all the commissions, and once the feedback is given there isn't a body to implement it. There is not an entity that coordinates and passes the inter-territorial policies. So what happens? Each one gets informed within its ministry on the results, isn't it. And can even do that lateral effort, but in the end there is that lack of a coordinating body. - (Informant for IR)

According to the informant for IR, what happens with some ratified documents such as the UNCRC is that each body or governmental department is left to their own devices in interpreting these guidelines. There is no coordinating body ensuring that all those affected by the guidelines interpret them in a similar manner, and because there is no coordinating body, this leads to a great deal of confusion and variations in what is support granted and provided. Similarly, there also no body that monitors the implementation of these guidelines. This was a criticism previously highlighted by the OECD (2003). Another limitation highlighted by this informant was the fact that ministries do not communicate adequately with one another. This is the source of many problems, because this division between departments filters down through the different tiers of government and civil service. She stated that there is no integrative

measure that brings ministries together. Each ministry has its own budget and its own priorities, and works independently. Even if different ministries and their employees are working in the same area, they do not work together and in an integrated fashion, unless specific work groups are formulated for this express purpose. What is needed is a more widespread means of fostering better communication between government departments.

Now we have the treaty body reform, which everyone is now talking about. That decision is so that member states have a common core document. Which is a common treaty for the application of all conventions set out by the UN. So the 7, soon to be 8 with the Convention for the rights of people with disabilities. So what happens now. As all countries have to adopt that common core document. Now more than ever we feel the need for an entity to coordinate the measures of a common core document. What is a common core document. It is a common core information, that is specific to all the measures to be implemented. The states would complain that it is a lot of work, and it is! It is. For who has been involved in elaborating the reports it is. It is a lot of work for a member state that has little financial and material resources, to apply all 7 enormous treaties. But states would complain that some measures would overlap and contradict themselves, which is why they came up with the common core document. (informant for IR)

This informant suggested that by having an organisation that works transversely with these international treaties and would coordinate their measures, would be a tremendous improvement to their implementation. Having this implementing body would allow measures to be implemented consistently at all levels of government and in an uniform fashion across departments. Furthermore, as stated above one of the main problems of the UN Conventions is the fact they often overlap with one another, which can be confusing. Not only would this implementing body be beneficial for tackling these issues, but also for constructing a common core document that incorporates all the common core measures of all conventions.

Our legislation is very good. It is easy to produce these multi-coloured and great reports, because we have good legislation. The problem always comes in the implementation. So we do not need to lie in the reports, because the legislation is there. The problem is in the practice when they ask to provide statistics and so forth. That is when we have many problems. Because the implementation isn't the same as the formulation. (informant for IR)

The informant above highlighted that there is a difference between policy and practice. Whereas written policy and legislation are a step in the right direction, the steps that follow in the implementation and practice are not necessarily going in that

direction. This is due to the flexibility one has in interpreting and applying these measures, and the lack of support in implementing them. As discussed above, one of the main influences on policy and legislation, other than the government, was the UN's Standard Rules on the Equalisation of Opportunities for People with Disabilities. According to the informant above, as well as being outdated these guidelines are further hindered by the lack of support for their implementation. As stated before, and supported by this informant, a significant amount of responsibility lies in the hands of these policy implementers.

4.2 Conclusion

This chapter sought to explore the international guidelines the interviewees worked with. It was surprising to find, at the time, certain UN guidelines were outdated in terms of their conception and approach to disability. Not only are they outdated, but also inconsistent. The ICF has one way of conceptualising and approaching disability, UNESCO has another, and the Standard Rules for the Equalisation of Opportunities for People with Disabilities have another. The Standard Rules seemed to fall a long way short of its purpose. By directing educational guidelines at integration they do not promote equalisation of opportunities. It forces people with disabilities to adapt themselves to the current educational structure, rather than adapting the educational structure to fit their needs. The 'equalisation' suggested in this model alludes to the process of normalisation which, as discussed in works by Stalker et al. (1999), can be viewed as oppressive.

Within Portugal the social movement of disability is not as strong as that in the UK, for example. In fact, as has transpired through the interviews, awareness of the social model of disability is quite limited. Hence, although the UK probably has to adhere to similar international guidelines, the conceptions of disability suggested by Save the Children in British society and in the literature on disability in the British context are far more advanced than those proposed in the Standard Rules. As a result, countries such as Portugal will probably not develop their legislation and guidelines, until international legislation says so.

In addition, many of these international guidelines fall short from providing effective implementation tools. As mentioned by various interviewees, Portugal has all the measures and legislation in place to meet international guidelines, however, these measures fail to achieve their purpose. Barnes (2003) suggested that the ICF, for example, failed to suggest how to address environmental barriers. More theoretical studies, such as that by Allan (2006) show the difficulties we have in grasping certain concepts. The informant from the field of IR also suggested that one of the main limitations to implementing these guidelines is the lack of coordination bodies to articulate and implement these measures or to monitor them. Not only do international bodies need to reflect on the measures they propose and articulate more clearly how to implement them, but the Portuguese Government needs to invest in setting up a relevant body to follow and support the implementation of these guidelines. Recently, there has been a UN Convention on the Rights of Persons with Disabilities (2007) which addresses these issues and promotes inclusion. It would be interesting to view the impact of this on member states and their approaches to disability.

To summarise, international guidelines have been very influential on Portuguese policy, particularly in the field of children with disabilities. Their principles have resonated throughout the interviews and national policy documentation. Some of these measures included in the international guidelines, however, seem to include outdated principles or fail to illustrate how these measures can be implemented effectively. Consequently, they could result in outdated and inefficient policies, not to mention the lack of organisational bodies to effectively monitor this implementation. The following chapters will explore these issues in more detail.

5. Identifying the Context of Policy Decision-Making: Governmental Plans

5.1 Introduction

In addition to international guidelines, governmental plans were also heavily identified by senior level civil servants as influencing policy decisions concerning children with disabilities in Portugal.

We have a legislative function. We determine our activities plan of the Directorate-General, and within the Directorate-General, of each of the Directives of Services. This is done in accordance to that which is written in the Program of the Government and is the Great Options of the Plan. We determine the Activities Plan of the D-G, and in the D-G, of each of the Directorates of Services, in accordance with the PG and the Great Options of the Plan (GOP) (Informant for Regimes)

These policies are defined in the Great Options of the Plan and the Program of the Government. The State's organisms of direct administration put forward proposals and measures for the Great Options of the Plan. These Great Options are done through the resolution of Council of Ministers. It's in these Great Options that measures exist, measures that are to a certain extent important. Development strategies for the country that one Government puts forward, however, can then be changed by another, or measures that were being implemented can also be replaced. (Informant for Social Action)

Senior level civil servants mostly tended to identify guidelines stipulated in governmental policy plans and manifestos. These are mainly found in the '*Programa do Governo*' (Programme of the Government - PG) and the '*Grandes Opções do Plano*' (Great Options of the Plan - GOP), which are the two main instruments by which the government disseminates their policy plans. The PG is the Government's manifesto for their term in office, whilst the GOP is the policy plans developed by the Government for each year. These two sets of guidelines, especially the GOP, have been identified as the main influences on policy-making by senior level civil servants. As discussed by the informant for Social Action (SA) above, organs of the state that work directly with the government, e.g. the Directorate Generals (D-G), work on plans regarding key policy areas advertised or dictated by the government.

The current Portuguese government is the 17th constitutional government since the end of the dictatorship in 1976. This research focuses on existing policies and policy changes occurring in the period between January 2002 and 2005, which coincides

with the period leading up to the interviews conducted with civil servants, between September 2005 and January 2006. This period includes the change of government in March 2005, in which the Socialist party replaced the Social Democratic party in government. The aim of the current project is to highlight the impact that both the former and current administrations have had on the informants and the policies studied here. Within this period there were in fact been three different Constitutional Governments and thus three separate Government Programmes (manifestos). Of these three governments, two were Social Democratic and one was Socialist. It is important to note that the most recent Social Democratic government resulted not from an election, but was instituted due to the resignation of Prime Minister Jose Manuel Durao Barroso (17th July 2004) in order that he could take up the role President of the European Commission. As a result, these two governments and their PGs are very similar (if not the same) in most areas and will thus be analysed together. The Program of the XV Constitutional Government highlights the proposed changes regarding areas within social policy which resulted from the change of administration following Durao Barroso's resignation (2004). Interestingly, and perhaps due to their routes in the labour movement, the Social Democratic programmes refer to the section of their PG encompassing most social policy areas as 'Reinforcing Social Justice and Guaranteeing Equality of Opportunities,' which highlights their underlying approach to social policy.

In addition to the PGs, the government formulates the Great Options of the Plan (GOP) which elaborates the policy plans for a given period of time that usually amounts to a year. As elaborated by the senior level civil servants, the PG highlights policy areas each government would like to tackle. The PG is a platform for civil servants, especially at a senior level, to submit proposals and work towards incorporating these proposals into the GOP. The GOP, in turn, establishes specific policies that are to be adopted by civil servants and the governing parties. The guidelines within this plan are orientated at all levels of the civil service, as opposed to just senior level civil servants. However, as highlighted above, these guidelines may vary in influence and weighting within different sectors of the civil service and their function. Some civil servants compete to have the guidelines changed, whereas others just implement them in their work. Between 2002 and 2005 there were four

GOPs, all of which included policy changes relating to children with disabilities to varying degrees.

This chapter shall start by exploring what provisions were highlighted in the PGs between 2002-2005 regarding children with disabilities. In addition, it shall explore what the GOPs say in the context of educational policy and policy relating social security that is aimed at children with disabilities.

5.2 Programme of the Government (PG)

The period of 2002-2005 incorporated two Social Democratic governments led by Jose Manuel Durao Barroso (2002-2004) and Pedro Santana Lopes (2004-2005). These two governments are treated together, because they had such similar PGs, with, the Santana Lopes administration representing a continuation of the policies begun under Durao Barroso's premiership. Within their PGs, social policy recommendations fell under the heading of 'Social Justice and Guaranteeing Equality of Opportunities', whilst education policy had its own grouping. The social policy recommendations of the most recent Social Democratic under Santana Lopes government fell into the following categories:

- Health
- Social Security
- Family and the Child
- Equality
- Immigration
- Cities, Development and Local Administration
- Housing
- Defending the consumer
- Education
- Youth
- Sport

In addition to these areas, the government prior to this under Durao Barroso also included the areas of Ethnic Minorities and Immigration, Cities, Organisation of Territory and Environment, and Family (instead of Family and Child), as part of their areas of focus. However, not all of these areas referred to policies relevant to children with disabilities.

Within the Durao Barroso government's PG there was only mention of policy changes directly relevant to children with disabilities within Social Security, Family, Youth, and Sport. With reference to Social Security this Government mentioned there was a need to revise the Base Law on Rehabilitation, so as to effectively activate the support and integration of persons with disabilities. This law was set up in 1989 and has not yet been changed. Its aims were to promote and guarantee the rights written in the Portuguese Constitution relating to the prevention of disability and the treatment, rehabilitation and comparative equal opportunities of persons with disabilities. The main aim of these revisions is to speed up support and integration for people with disabilities, whilst promoting incentives for employment in tele-marketing and home based employment. In addition there was a plan to create new social benefits for supporting those with severe disabilities. To a certain extent, this emphasises an eagerness to orient disability-related policies towards employment.

Within the area of family policy there were also proposed changes. There was a guarantee for more accentuated, affirmative action for social benefits for children that are incapacitated or with disabilities. This PG placed great emphasis on initiatives for young people to promote their participation. There was particular reference to young people with disabilities, and the development of specific measures to support them. Furthermore, emphasis was made to promote the participation of people with disabilities in sport through the provision of support. It is important to note that significant emphasis was placed, in previous years, on the support for athletes competing at the Sydney Olympics and Paralympics. In terms of the latter the support costs were divided between the Secretary of State for Sport and the Ministry of Labour and Solidarity (GOP, 2001).

In addition, it is important to note that, at this time, EU strategies such as Barcelona Agreement (2002) to address the issue of (gender) equality, changing family structures, work/family balance and childcare had recently been put in action. In fact, the Barcelona Agreement stipulated that by 2010 at least 90% of children between 3 years and mandatory school age and 33% of children under 3 years of age had to be in some form of childcare (Barcelona Agreement, 2002: Part 1; 32). Although this was not highlighted in the interviews, the influence of such EU level initiatives seems to be reflected in the governmental documents analysed here. It is also important to note that Durao Barroso's position as President of the European Commission throughout this period, meant that his party was acutely aware of developments at the EU level and had a keen interest in implementing European policy measures in Portugal. Therefore, it is no surprise that these measures were also included in the PG of the Santana Lopes administration. Most of the changes suggested by Santana Lopes's government were the same as those suggested by the previous government.

The 2005 socialist government has placed more emphasis on policy suggestions relating to children with disabilities than the previous social democratic governments. From the eight social policy areas proposed (more and better education, valuing culture, labour and job market, social protection and fighting poverty, health, families, equality and tolerance, inclusive immigration policy and youth policies), four covered policies that were of interest to children with disabilities. These were as follows:

- More and Better Education
- Social Protection and Fighting Poverty: more future, better present
- Families, Equality and Tolerance
- Youth Policies: citizenship education, promoting democratic participation

This government planned to invest in improving and sustaining the Portuguese education system from pre-school to secondary school. Within those plans there was mention of altering the evaluation system for students in need of support programmes and students with learning difficulties. As stated within their PG:

The principal aims are to have 100% of 5 year-olds frequenting pre-school; a drastic reduction in the unsuccessful of basic education and the abandoning of the transition into secondary education; guaranteeing educational needs and special education; the offer of programs of complementary education and social support in all the scholastic groupings.

In addition to maintaining the goals of the Barcelona Agreement, this government intended on investing and improving schooling and catering for those with learning difficulties and support needs. These initiatives hoped to improve the success of pupils at school and support for them to do so. In general, the Socialist PG advocated principles of inclusion and initiatives to tackle social exclusion and poverty. These initiatives included child care, de-institutionalisation of persons in care and alternative integrated support and measures associated with child protection and children at risk. This government aimed at fighting discrimination and promoting autonomy and participation of young people. In addition, social protection was another significant area touched upon by this PG. There were plans to tackle discrimination and promotes an inclusive society. These measures included: defining benefits for Disability, Invalidity and Dependency Support according to the levels of severity of impairment and the vulnerability of families, as well as developing a new support regime for single-parent families.

Family is an important element in structuring Portuguese social policy. This factor was clearly manifested within the PG of the Santana Lopes government. It recognised the changing dynamics of the family and their structures and intended on exploring their typologies in order to provide them with the appropriate provisions. Furthermore, it planned to develop public policies through that promote social justice and eliminate the factors encountered by socially vulnerable families. There was also an intention on promoting a work/family balance as well as equality and a public-private partnership to execute and develop social policy.

This PG has distinguished ‘youth’ as being a separate and unique area of policy requiring attention. Within this area, the majority of the recommendations were aimed at participation and citizenship. These recommendations included providing incentives and motivate participation for young people, as well as, developing student associations and youth municipal councils. Furthermore the government intended on providing incentives for the geographical mobility of young people in

Portugal and Europe to support young enterprise and to tackle the job insecurities for young people. There were also plans to facilitate the access of young people to housing. All-in-all these changes indicate the governments' acknowledgement of the importance and need of having and modifying policies for all children, young people and persons with disabilities. However, young people were clearly given more attention than the other groups covered.

5.3.1 Great Options of the Plan (GOP): Education

At this stage I would like to make early childhood intervention effective, as a measure to tackle social exclusion, being still a measure of social cohesion. That is an important area. All that, that is developments regarding the quality of education give, therefore, the issues that are centred in the curriculum. In Portugal, the access to education at this point is guaranteed. But the problem is in the quality of the service given. Then the other area in which we are working is that of the transition of the school into employment. It is an area of great importance. And then there are the technologies for support. Isn't it? That has to do with software and... and... all the technical aids, the technologies for supporting mobility and communication. I can say, because in terms of social policies linked to special education, this could be the four or five current priority areas. In addition we also started having questions about the vocational training of adults, the vocational training throughout life, which is an area we also have started being preoccupied with. (Informant for SNE)

When asked what the social policy priorities were within the area of Special Education, the interviewee for SNE within the Directorate for Innovation and Curricular Development (DGIDC) highlighted the following areas:

- Early Childhood Intervention (ECI)
- Quality of Education
- Transition into the Labour Market
- Technical Aids

There were a number of issues and assumptions underlying the policies advocated in these areas. For example, the informant in question regarded ECI as a form of tackling social exclusion and promoting social cohesion. Hence she indicates that the underlying priority is actually tackling social exclusion, rather than just establishing an effective system for ECI. She also highlighted that access to education was not an issue. The problem was instead the quality of education available. However, as illustrated by the vignettes, this may not always in fact be the case. What this

informant refers to as access is in fact *availability*. There are places available, the problem is in accessing them. In reference to the vignettes, this informant had highlighted that there was a need to access information regarding ones rights, but resources for support are available. Hence, access to education is still an issue, as is quality. In terms of quality, this area could also reflect issues of inclusion vs. integration. As suggested by the informant for Social Action (SA) of the DGSS (Directorate-General for Social Security) resources and support fall short of that which would be necessary in order to make inclusion a reality. Integration, however, is more a realistic aim according to her. This notion again highlights that social exclusion is expressed as one of the main problem areas regarding children with disabilities, something which resonates through the other priority areas. This suggests that policy, in the words of the informant above, is taking more of a social-based direction.

In looking at the PGs it seems that the Socialist government had the biggest influence on this informant, as she seems to highlight areas presented in their PG. However, when looking at the GOPs between 2002-2005 the influence of the Social Democratic administrations is also evident. The GOP 2003, was the first of the GOPs put forward by the SD Government. Its policy suggestions were as follows:

- Give social value to businesses and institutions that incorporate the integration of young people with disabilities
 - Support for the development of physical activity for young people with disabilities
 - Guarantee the education and familial and social integration of children and young people and adults with hearing, intellectual, motor, and other disabilities that require special action measures
 - Implement an early childhood service for all disabilities, including home support
 - Support for the transition of school into employment for young people with disabilities
 - Adapt scholastic structures and equipments, so as to facilitate the accessibility for children and young people with disabilities.
- (GOP 2003)

Although special education was not specifically mentioned in the PG, in this GOP there was a section on Special Education. There were plans to revise the legal regime for special education and regulations for Special Needs Education (SNE), in order to improve its quality for those who have permanent SNE. In addition, there was a plan

to invest in the training of teachers and also research into developing educational environments and teaching instruments. This GOP invested in policies regarding children and, more specifically, young people with disabilities, providing them with a distinct identity within the policy framework. This identity, however, seems to concentrate mainly on young people with disabilities and their transition into the labour market, where again the latter was a major policy area for people with disabilities. There were, however, some very progressive policies regarding awareness-raising, accessibility and support for young people with disabilities, highlighting a significant change between this government and the previous government. There was even mention of tackling social exclusion regarding young people with disabilities. Children, on the other hand, received less coverage. An area of interest, although not as prominent as young people, has been policies relating to early childhood intervention, which starts the framing of one of the main policy areas regarding children with disability.

Although the measures presented in the GOP 2004 could be construed as being directed more at social security rather than education, there were a few provisions referring to education. Aside from placing great emphasis on rehabilitation, there was mention of launching projects such as the ‘Alert School!’ project, which is still running to date. The ‘Alert School!’ competition:

- is directed at students of primary and secondary school under the pedagogic orientation of teachers
- Envisages the active participation and intervention of students listed as encountering barriers (social, communication, urbanistic and architectural) and the presentation of proposals regarding solutions and initiatives that contribute to ameliorating the quality of life of people with disabilities or that are incapacitated.
- Contemplates the attribution of prizes by district/region and national for the best work.
- Still foresees diplomas of participation for schools, students and professors, as well as, when justified, honourable mentions.

(SNRIPD, 2008)

The function of this project is to stimulate the development of proposals, on eliminating barriers encountered by children or young people in primary and secondary education. In addition, it will evaluate their efficacy at fulfilling their

aims. Consequently, the most successful proposals shall be fully funded and implemented.

As listed above the barriers encountered by children in education are usually of a social, communication or architectural nature, and are encountered most of all by people with disabilities. As highlighted above, the ‘School Alert’ Project is a project run by SNRIPD and has the aim of raising awareness and mobilising students to participate in overcoming discrimination encountered predominantly by people with disabilities. This project also aimed at promoting equality of opportunity and participation, resulting in the type of policy solutions that would be advocated by the social model of disability set out in previous chapters. Furthermore, this has been one of the very few occasions in any of the documents covered where children, and in particular children with disabilities, were referred to as being full citizens with full rights, rather than as dependants. ‘Alert School!’ is a public competition which invests in projects presented by schools and other such youth oriented institutions, that identify what barriers exist to full participation and propose changes to remove these barriers. Hence, it responds to the needs identified by the public. As a result, it is clear that the changes highlighted above also suggest an understanding of disability orientated more towards the social model of disability.

Other than these sections, there was a brief mention of provisions of interest to children with disabilities within some other sections of the GOP 2004. One was improving the dissemination of information whilst taking into account the issue of accessibility to information and services for people with disabilities. Books in Braille and other accessible reading materials would be made available to people with hearing or visual or impairments. There was also brief mention of reforming Special Education, where there was a call for an preparatory project to develop a new Decree-Law establishing a regime for Special Education and measures associated with this. It was suggested that there would be an open discussion to establish a regime for Special Education, as well as socio-educational support for children and young people. This support would be based on adaptive measures for SNE, orientated at children and young people with disabilities. These suggestions indicated

an inclusive approach to changes in policy and an orientation towards inclusive schooling. There was an emphasis later on in the GOP 2004, on supporting the creation and development of adapted learning conditions for pupils with physical or sensory disabilities. There was also mention of making the curriculum for pupils with disabilities accessible via ITC (Information Technology Communication) and improving support for pupils in Primary, Secondary and Higher education. It seems that promoting accessibility in general was a priority in this GOP. However, it is important to note that this promotion is aimed at 'citizens' with 'special needs'.

As can be seen, although the PG for the SD government does not reflect the priority areas highlighted by the SNE interviewee, the equivalent GOPs reflected everything she said. There was a mention of early childhood education, quality of education, transition into the labour market and technical aids. Furthermore there was mention of accessibility, and access to education which seems to be an area played down by the informant above. In fact, it seems that access to education was emphasised more than quality of education. Perhaps this is due to the issue of accessibility being outdated or overridden since the GOP 2004 belonged to the previous government and the interviews coincided with the GOP 2005-2009, which had a different emphasis from the previous programmes.

The GOP 2005-2009 has remained true to many of the provisions set out by the PG covering this period. Youth has been a policy area of great prominence, having a section on 'Investing in the Young People' included in the relevant GOPs. However, as highlighted before, this does not necessarily represent people under the age of 18. This investment entailed initiating various programs orientated at young people. These include investing in transposable and multidisciplinary policies, which would be covered in a National Plan for Youth. However, if we were to look closely at the measures associated with these policy suggestions, one finds they are mainly directed at employment. Furthermore, that provisions for those who do not work, and are not at working age, are orientated at preparing them for the labour market. This was the orientation of youth policy. As touched upon in the GOP 2004, young people would again be encouraged to form youth and students' associations, through the National

Programme for Supporting Associations. Furthermore, there were plans to have a National Programme for Volunteering to increase social awareness and value, and another Programme for Youth Mobility aimed at geographically mobilising young people. These programmes would take into account of globalisation and develop international dimensions to youth policy by investing in bilateral and multilateral partnerships to enable this goal to be realised.

Within Portugal there is a Portuguese Institute for Youth (IPJ). It was felt by the Socialist Government that there was a need to restructure the IPJ and create a new Inter-Ministerial Commission for Youth. In comparison to the existing criteria for the IPJ, the planned changes are more orientated at international exchange and also the development of civic duties. It is clear that these policies are aimed at the transition into adulthood of young people, rather than adolescence. It seems that the government identifies youth policies at enabling young people to become adults, rather than at policies which may enable young people to develop or to lead more fulfilling, rewarding lives while being young.

Other than the section specifically on youth, the GOP 2005-2009 also touched upon children and young people and people with disabilities in other sections that are relevant to education. In the section on family policy, the GOP mentioned the will to adopt flexible and adaptable measures to aid workers to effectively care for their children whilst still taking part in the labour market. In the sections on 'promoting employment as the nuclear pillar of social and territorial cohesion, of equality and inclusions', the GOP highlighted various policies relating, whether directly or indirectly, to children with disabilities. These included creating crèches, de-institutionalising 25% of young people, continuous support for dependents (mainly the elderly), researching the legal protection regime for the liability of disability within family protection and consolidating and developing the ECI System through education, health and social security. Quoting from the GOP, the aim of education policies is to:

reinforce and rationalise human resources and measures for the pedagogic use of new technologies, adapting curriculum for primary school education in order to appropriate it to

the diversification of Special Needs Education, instigate teaching sign and Portuguese language to people with hearing impairments, and finally, elaborate legislation establishing the adequate support for people with disabilities in higher education. (GOP 2005-2009)

The GOP 2005-2009 placed significant attention on schools and their curricula. Part of these changes included developing the 3rd edition of the 'School Alert' Project described above, as well as, reviewing the maximum age at which one can be considered a young person with disabilities in order to receive the appropriate benefits. There was also an aim to promote the use of Braille. This GOP placed significant emphasis on young people and the transition into work, which correlates with what the informant for SNE stated. Furthermore, there was discussion of social cohesion and emphasis on improving the quality of education through curricula, which highlights the areas that the informant mentioned, that weren't included in the previous GOPs. The informant for SNE later in the interview also explained that she was developing a Programme for Sign Language, which although there she stated this provision was available, there seemed to be a need for developing it further by establishing a Programme for it. This provision was also mentioned in the GOPs. It is clear that this informant's identified role extends from the GOP, as she has managed to adopt all the key terms highlighted with the GOPs.

Aside from the GOP, there is also the legislation and policies drafted by the government. Whilst the fieldwork for this project was being conducted, there was an announcement made by the government that every school was to have a Special Needs board. Previously schools had independent specialists visiting periodically to aid with Special Educational Needs. Now there was to be a panel of specialist(s) for each school:

The GOP still has to do with what is asked from us. For example, it wasn't in our plans to do these Panels for Special Education, isn't it? We made the plan in September, in December it was announced. Therefore we need to always adapt and alter and change. There needs to be a lot of flexibility in all this. So we need to reorganise ourselves, so there are colleagues more specialised to do this, others not so much. Let's say in terms of groups, there needs to be a bit of a reorganisation of work and flexibility to in the end respond to what is asked from us. (Informant for DREL)

As can be observed, this informant is slightly less clear about her role in this process, than the informant for SNE. This is probably due to the legislation being fairly recent

and still being developed at the time of the interview. Furthermore, this informant was not involved in drafting this legislation nor did she have a specific vision for it. As discussed in the introduction, schemas are mental frameworks that give order to social information. These mental frameworks develop and become more idiosyncratic with experience. Since the informant for DREL has limited experience regarding the Panels of Special Education, she has an undeveloped schema associated with this process. This would lead to her using existing schemas to form this one. However, throughout the interview it was clear that the schemas that were activated were based on legislation and set guidelines. Contrary to the informant for SNE who highlighted measures within international guidelines and the PGs and GOPs, the answers of the informant for the DREL mentioned measures similar to that existing legislation. As will be discussed further in the section on legislation, this was usually observed with lower level civil servants.

Special Needs Education was described by the informant for SNE as a subject area, like French and English. This was an interesting analogy, because English and French are subjects that are taught, whereas Special Needs Education is a measure to support education across the curriculum. Although one can study Special Education as an academic subject and get a degree in this area of specialisation, its application differs from that of French and English within the context of young people's schooling. It is also interesting how this interviewee seemed to associate Special Education with foreign languages. Perhaps she views this Special Education as a foreign concept too, meaning it may not really be a mainstream concern in her conception. Furthermore, distinguishing special education as a separate teaching area, may lead to it being conceived as a segregated subject area, rather than an integrated and inclusive educational measure. This, in turn, may lead to measures that would result in the segregation of students with special needs within mainstream schools. Consequently, if these Special Education Panels view special education as a separate teaching subject, they too may result in segregating, rather than integrating and including student with special educational needs.

In terms of Education, the PGs, the GOPs and the government itself seemed to have a direct influence on the interviewee for SNE, who works within a Directorate-General. The information she provided in her interview closely mimicked government policy plans and objectives. This informant is a professed advocate of inclusive schooling, and has stated that all measures are in place for this to occur. The only limitation, she argued, was that human resources are limited, which was being tackled by introducing Special Education Panels for schools. However, although on paper these proposed measures may sound adequate, it is necessary to explore the precise meaning of these measures. Key words and phrases within the policy documents have a variety of possible interpretations and understanding. It seems that the informant for SNE views Special Education as a separate teaching area, similar to that of foreign languages. If this is the case, then perhaps these measures are not inclusive as they are presented as being. In this context, one starts to understand why although (as was claimed by various interviewees) ‘all legislation is in place to meet the needs of people with disabilities’, the reality is very different. It is not just a problem of limited resources, but also a question of what disabled children’s needs really are. This point is of crucial importance in this study and shall be discussed in greater details later on in this chapter and in the following chapters. The informant for DREL hardly mentioned Governmental Plans, but rather she touched upon notions presented within legislation. However, her views of special education were more about adaptive measures and how to support the needs of children with disabilities and their families with available resources. Furthermore, since she was not in a managerial role, she was not concerned so much with running staff and meeting quotas, but rather meeting the needs of the public.

5.3.2 Great Options of the Plan (GOP): Social Security

Of these informants only two made direct reference to the GOP and PG as a guiding influence. They were the informant for Social Action (SA) and the informant for Regimes.

As I said, you are in the area of social action. Usually, 4 in 4 years there is a new Government cycle, each cycle presents a new Program of the Government. I referred that these Programs are a compilation of possible social policies to be developed. In this, it is important to highlight that new policies have to not only be in accordance with current

legislation and national requirements, but also European. The new Government, for example, wants to give priority to policies regarding children and young people, the problematic of disability, elderly and dependents. There are policies in the GOP that are not specified in the cycle of the Government, but are longitudinal. But there are certain alterations from Government to Government, or party to party, that result in delays and problems with their implementation.

The normative framework or the technical framework, is when we do these agreements of cooperation, between District Centres of Social Security. They are the concentrated services from the ISS that will assess if the Institutions in that establishment, be it a crèche, an ECA (Extra-curricular Activities), a home, residential care. This is relative to people with disabilities and other provisions we have. If that provision is to be developed, it will be developed with the regulations in terms of organisation and function of establishments and the framework of the people that are required in terms of the provision in itself. So, the obligations of institutions are defined, as are the obligations of Social Security, and what is the amount of the funding from Social Security is defined too, as is the amount to be paid by the users that provision. The money that is given to this cooperation is based on the priorities defined by the Government in the GOP and PG. (Informant for SA)

Within the area of Social Action, there is a clear affiliation with the GOPs and PGs. However, the field of Social Action, according to this interviewee, seems to be concerned with developing public-private partnerships. Since the Portuguese state does not have the means to provide integrated social services, it develops protocols of cooperation with the IPSS (Private Institutions for Social Security). These protocols are aimed at bridging the gap of lacking services. These IPSS are granted support if they provide services within the target areas of the government and the state. The prioritised target areas are generally defined within the GOPs and PGs. The interviewee quoted above took a different approach to policy to the interviewee of SNE. Perhaps because Social Action is a widespread area that is not exclusive to children nor disability, she has a less clearly directed or consistent approach when covering all policy areas. Furthermore, Social Action is more concerned with the process of developing partnerships with the IPSS, rather than on meeting the needs of the public. According to this interviewee, the priority areas set out by the government are those regarding children and young people, and the problems posed by disability, the elderly and other dependents. These are the areas where private-public partnerships are prioritised.

The informant for Regimes for the DGSS took a slightly differentiated approach to the issues of disability in children to that of the informant of SA. Although this

interviewee relied heavily on legislative definitions to define the term 'children with disabilities' when highlighting what factors influence her professional role, it has predominantly been the government.

So, the PG has outlined areas of intervention. It has various Chapters, isn't it? In the chapter on Social Policies you can find all that information. So we select... One of the great items that is selected here is a sustainable social security system. Here it is and this sustainability refers to financial sustainability. So financial sustainability is underlined. Actually, if we want to read... it says its time to construct a third generation of social policies for Portugal, that correct recent errors, that have principles based on the guarantee of economic, social and financial sustainability for the Social Security System, that represent a new impulse for social protection, each time more based in the positive differentiation in the fight against poverty. Therefore, these are the great measures. The positive differentiation through treating in a different manner or treating in a way... or a better way to treat those who need it more. So fighting poverty, but also being preoccupied with the economic, social and financial sustainability of the Social Security System. How do we act in targeting the dehydration at pension level? We can, for example, act at pension level. How? Well the Government directs us to limit the large pensions. Or be it, not to permit, for example that people have, receive pensions with a value superior to a set amount, ummm... an amount is already above the average. After, another way of guaranteeing a sustainable social security, is for example, through creating conditions for people not to retire early. (Informant for Regimes)

The PG was one of the main policy instruments highlighted by the informant for Regimes. This informant is situated within the Ministry for Social Security, stressed that sustainability was one of the main objectives for social security. It seems that the main areas emphasised were the rise in pensions and cracking down on fraudulent benefit claims. Although the interviews were mainly concerned with policies regarding children with disabilities, the issue of pensions and fraud arose frequently within this interview. In addition to sustainability, there was to be affirmative action towards tackling poverty, in which provisions and measures were to be orientated at those who need it the most. This measure also contributes to building a more sustainable social security system. Rather than having a universal system, they would opt for retrenchment of the current levels of welfare provision through means-testing and the orientation of provisions at those who need it the most. The informant for Regimes also highlighted other, more specific areas of intervention:

Then another direction that is highlighted in the PG is fighting poverty and social exclusion. A way in which, so... after this can be materialised, the government gave us a task to develop sustainable processes of personal development and prevention of poverty and exclusion, the fight against unemployment and an investment on policies orientated at qualifications, shall be the structural basis to the intervention of the Government. In other words, the insertion into work placements and the best possible qualifications. Then we have another direction that is to reinforce social protection with more rigour and justice. And so

we enter in the branch of functional performance, in which I place myself in functional terms. Erm... Within this framework, the government wants to introduce mechanisms of moralising the system. Therefore, it wants to introduce instruments to penalise the accumulation of individual instalments or income or pensions. Reinforcing justice in the attributing unemployment subsidies, not promised for example, to workers systematically refusing an insertion in the labour market. Err.. So, inspecting sick leaves, unemployment subsidies, the attribution of various instalments. So, there is an investment in inspections to see if people are receiving these subsidies are those who deserve it, and therefore pushing away a bit fraudulent situations. (Informant for Regimes)

In addition to poverty, social exclusion was also identified as an area of intervention. The informant for Regimes highlighted the introduction of processes to support personal development. However, she also emphasised that gaining qualifications and, moreover, integrating individuals into the labour market were the main focus areas. This integrative approach seems to dominate social provisions, especially youth policy. In spite of this, when referring to poverty and social exclusion, the informant above does not highlight the disabled or any other social groups that encounter these conditions. It is clear that this informant was uncomfortable discussing this topic. Possibly this is not really her area of expertise, and as such she does not have a strong schema regarding this area due to her limited or specialist experience within this area. Furthermore, she kept returning to the issues of pensions and especially social security fraud, explaining that it was in those areas that she placed herself functionally.

The following chapters will discuss the issue of psychological schemas and how stronger schemas tend to manifest themselves the most. Although this interviewee knew she was being questioned about policies regarding children with disabilities, she tended to mention areas that were not of direct relevance to this. As will be argued below, although she does occasionally mention provisions orientated at disability and dependency, she often reverted back to fraud and pensions and also to the issue of transparency:

Then, we have also been asked within this domain, what I had told you. Review the support to disability in accordance with that criteria, reviewing protection to invalidity, evaluate the support regime for dependency defining a better adjusted model to new long-running social risks in the face of prolonged care. Conceive a new support regime for low-income single-parent families. So, as you can see there are various ways in which we can achieve this objective of reinforcing social protection with more rigour and justly.

In the GOP you will not only find the balance of measures foreseen for 2002/2004 but also what is intended to be done or was foreseen to be done for 2005 and the policies to be made in 2005 and therefore there is here a series of associated measures of social policies in which one will find some aspects that are referent to the disability protection and dependency protection. In a generic manner, these are the main priorities. Then there are other priorities and those are found in the GOPs. In terms of children, children with disabilities and disabilities... There is here a priority in the PG to revise the protection of disability. Not children specifically, but rather the disabled citizen in general. That is a priority that is stated here in the PG and is given autonomy in relation to the rest. But it does not appear to me to be specifically orientated at children with disabilities. It is in relation to the general citizens with disabilities. That measure also has been referenced in the base law, because it talks about a protection in the domain of disability to citizens in general and not specifically children. Disability is either given autonomy, even in governmental policies or is included generically in the reinforcement of social protection. That is besides maintaining structures such as SNRIPD that have the vocation for this specific objective. (Informant for Regimes)

As discussed above, disability was an uncomfortable subject within this interview. When asked to define disability, this informant refused to give her own opinion and relied instead on what was stated in the relevant legislation. When highlighting possible changes in provisions and policy, support for disability and dependency was one of the items under review. The measures identified were mainly found under the umbrella of social protection. However, this interviewee was prompt in highlighting a distinction between children with disabilities and citizens with disabilities. She stated that, although children with disabilities fall under the umbrella of disability, this policy area does not specifically mention children and, hence, may over look them due to its ambiguous content in this area. Furthermore, she does not attach the term 'citizen' directly to the child, although she does attach that status to persons with disabilities. Within the legislation regarding disability there is a distinction associated with citizenship, and that is dependency. Dependency seems to remove an individual's claim to full citizenship. As a dependent one is no longer viewed as a citizen in one's own right but, instead, as the dependent of a citizen. If one has a disability and does not work, or if one is dependent on others such as family members, then one is no longer considered to be a citizen. Citizenship, therefore, seems to be employment-based in the understanding of this informant.

As stated previously, the field of Social Security incorporates a wide-range of areas, services and provisions. As a result, the GOPs covered a large number of policy

areas regarding Social Security, many of which were of relevance to children with disabilities. The GOP 2003 highlighted that the government's aims were to:

- Reinforce the positive differentiation of social provisions for children with incapacities or with disabilities
- Introduce an Integrated Support Plan for Young People with Disabilities. This will include: free youth card, prize incentives for businesses to hire young people with disabilities, specific voluntary programs to support young people with disabilities, free board in youth hostels for associations supporting young people with disabilities.
- Support actions orientated at transportation, developed for the mobility of people with disabilities and naming a representative for this sector for the National Council for Rehabilitation and Integration of People with Disabilities.
- Fulfil special support measures for young people with disabilities. These include special support to associations and institutions that support young people with disabilities and launching an awareness campaign for the integration of young people with disabilities.

(GOP, 2003)

Within the GOP 2003, there seemed to be an interest in supporting children with disabilities. Although it was not clear precisely what 'positive differentiation of social provisions for children with incapacities or with disabilities' meant, it seemed to imply there would be affirmative action towards provisions orientated at children with disabilities. Hence, priority would be given to these provisions. However, this was then followed by a series of provisions orientated at young people with disabilities. In the context of the GOPs, the term 'young' (as will be discussed below) seems always to be attached with active labour market policies, indicating that young people are in fact considered to be young adults and not children. Furthermore, if we look at provisions orientated at people with disabilities, they seem to be orientated at adults or, rather, adults with disabilities. Hence, the word 'people' seems to be attached to adulthood, rather than all human beings unless stated otherwise, and policies are structured and interpreted in such a way.

In addition, when reading these provisions, the perspectives of these individuals are directed less at children with disabilities themselves and more at the services surrounding them. When focussing on the affirmative action towards social provisions for children with incapacities or with disabilities, the informant for SA tended to focus on issues such as how to develop public-private partnerships to enable these policies. This area appeared not to be of great concern to the informant

for Regimes, as her area is cash benefits and fiscal policies. The informant for International Relations could possibly be consulted on what international guidelines say. However, what emerged from the interviews was that it is the IPSS which sets out what their provisions are, and are given funding on that basis. What the plans highlighted above from the GOP 2003 mean, is that funding for this year or governmental cycle will be orientated at the IPSS which offer these provisions.

Similar to the previous GOP, the GOP 2004 also places great emphasis on provisions regarding people with disabilities, with particular mention of young people with disabilities. The *Plano Nacional de Acção para a Inclusão* (National Action Plan for Social Inclusion - PNAI) alongside the National Plan for Employment (PNE) has been a great source for provisions. Under the title of 'Intervention Close to the Public with Difficulties of Insertion', this GOP has elaborated ways in which the PNAI can target these groups. These measures have been highlighted above by the informant for Regimes. She highlighted the investment of the government on developing sustainable processes of personal development and prevention of poverty and exclusion, where the emphasis was on work placements and individuals gaining the best possible qualifications. Since the PNAI is in partnership with the PNE, it is clear that the nature of provisions in this area would focus on employment. This was confirmed by the interviews.

When exploring the meaning of 'insertion' (*inserção* in Portuguese) this term was referred to as the 'insertion act' as it may be termed in English (PRIBERAM, 2008). When the term insert (*inserir*) was looked up, words such as introduce, merge, incorporate, implant and include were given as synonyms. Although the term insertion implies integration or inclusion, it seems to indicate more of a forced placement rather than a natural or symbiotic transition. Within the plans directed at the PNAI and PNE, is a plan for creating a social and professional support regime for people with disabilities in order to promote their employment. As a result, the majority of provisions are aimed at, adapted for and dedicated to 'insertion' of individuals with disability into the labour market. Hence, the measures regarding the PNAI are associated with employment and therefore the concept of inclusion

indirectly insinuates inclusion ‘into the labour market’ rather than into society more generally.

It was suggested that the Social Security system needed reform. Within these reforms, a development of a National Plan for Promoting Accessibility (PNPA) was suggested, as well as a Direct telephone line for ‘Citizen/Disability’ for related issues. Furthermore, as a result of the European Year of the Person with Disabilities (EYPD) in 2003 the GOP 2003 wished to develop the activities instigated by this initiative. Within the final report of the EYPD it was found that Portugal needed to provide ‘basic services’ for people with disabilities (European Commission, D-G Employment and Social Affairs, 2004: 18). As a result, Portugal’s national priorities, in association with the EYPD objectives, were:

- Promoting the awareness of the public in order to change attitudes towards people with disability
 - Ensuring that the principle of non-discrimination is applied
 - Promoting legislation affecting people with disabilities, and also its enforcement
 - Ensuring access to education for children and young people with disability
 - Ensuring that people with disabilities make full use of their citizenship rights, especially in relation to decisions affecting themselves and their families
 - Improving the quality of life of people with disabilities
 - Taking account of disability and its consequences
 - Information concerning disability and its consequences
 - Disability prevention
 - Guaranteeing people with disabilities the free choice of means and resources available
 - Promoting measures to ensure full access in the areas of building design, transportation and communication
 - Strengthening co-operation with the media
 - Promoting the social responsibility of social partners
 - Reinforcing public-private partnerships
 - Promoting the participation and creativity of people with disabilities through culture, sports and leisure
- (Perrin, 2004: 23)

The informant for Regimes did touch upon these provisions, although it was in association with the responsibilities of SNRIPD. Provisions reflecting these priorities have been put in place, and it seems that the intention is continue developing these initiatives. However, throughout these GOPs there is not a clear and direct link to the EYPD itself. This may need emphasising, especially when there are many documents on the EYPD available through the EU portal, where documents detailing these priorities are available in different languages, which may lead to confusion for

various individuals and entities. This could be a limitation in disseminating policy agendas and guidelines. When asking the IR representative for the DGSS about disseminating information from international organisations, she highlighted how there was a database on the Social Security website. All the relevant information is online and individuals were encouraged to follow it, including links to other organisations. However, conducting a search on this topic, the outcome rendered a series of documents that differed greatly between the English and Portuguese versions, and also from each other. This can be greatly confusing, especially if used as a tool for policy-making.

In the GOP 2004 there was mention of revising the Base-Law for Rehabilitation (n. 9/89). This Law was set up in 1989 and had not yet been changed at the time the interviews were conducted. Its aims were to promote and guarantee the rights written in the Portuguese Constitution relating to the prevention of disability and the treatment, rehabilitation and comparative equal opportunities of persons with disabilities. Resulting from a call to change this piece of legislation, there were plans to elaborate on revisions to this Base-Law. The main aim of these revisions is to speed up support and integration for people with disabilities, whilst promoting employment in tele-jobs and home based employment. Again this emphasises the eagerness of orientating disability-related policies towards employment.

There was also mention in the GOP 2004 of mechanisms relating to the improved monitoring of the living standards and integration of people with disabilities, especially through the network of Support Centres for Disability and accessibility. In addition, there were plans to change the legislative framework surrounding social provisions for people with disabilities, so as to tackle more efficiently the 'real' needs and rights of people with disabilities. However, given that these suggestions were intertwined with suggestions regarding integration into the labour market, they could be misconstrued as measures directed not at improving the conditions of disabled persons per se but at improving the overall state of the economy through the integration of people with disabilities into the labour market. Hence, these policies are directed at adults with disabilities, where needs and rights are directly linked with

employment. 'Ageism' seems to be a common factor within these policy provisions regarding people with disabilities. It is indirectly implied that people with disabilities equates to adults with disabilities unless otherwise specified as 'young people' or 'children' with disabilities.

The Portuguese State has public-private partnerships especially in the domain of social action. Hence, policies orientated at children with disabilities do not only regard children and their families but also what are called IPSS. These are institutions that work in collaboration with the state in providing or taking action where the state itself cannot afford to. However, within this GOP, although there was mention of intensifying the measures of the IPSS to fight isolation, solitude and poverty, there was no mention of disability. In fact, there were certain measures which were associated with to the IPSS. These were:

- Conceiving a legal framework for Social Action
- Modernising the registration of the IPSS
- Modernising and simplifying the installation, function and licensing regime for institutions and services for social action.

When viewing these changes, it is suggested that there was a need to structure a sustainable and effective network and framework for social action and hence IPSS. Perhaps as a result, disability was not a priority due to a need for a successful structure and administration in order to provide resources and support as effectively as possible. Although the IPSS was not linked directly to disability, there were various provisions mentioned within the sphere Social Action. In fact, the informant for Social Action identified them as the main means of intervention adopted by her department. She also suggested one of the main limitations of this provision was the lack of means to evaluate and inspect the agreements her department holds with the IPSS. However, she was a very enthusiastic supporter of this process of public-private partnerships as a means by which to overcome the lack of services in the social action arena.

Within the interviews there was significant emphasis on social networking for welfare provisions. There was also mention of this in the GOP 2004. It stated that it had an incentive to expand and certify a network of social support services and equipment for people with severe disabilities and their families. Various informants mentioned the creation of inter-departmental work-groups for similar services such as ECI. There were plans in the GOP to consolidate and develop a system for ECI that incorporates education, health and social security. Furthermore, there were plans to re-evaluate policies for social responses especially in the case of mental health. These social responses aim to reinforce the system of continuous care for the disabled population. a further suggestion was to guarantee the right of assistance in the case of illness, accidents, disability or with minors.

In the GOP 2004 there is a section on 'Rehabilitation and Participation of People with Disabilities' within the sections on 'Equality' and also 'Work, Employment and Vocational Training'. As opposed to policies aimed at 'insertion,' participation, integration and rehabilitation, in particular, seem to be the predominant themes in Portuguese social policy regarding people with disabilities. For example, the unit specific to and responsible for disability in the civil service is the National Secretariat for Rehabilitation and Integration of People with Disabilities (SNRIPD). With regard to work, employment and vocational training, there was more of a variation of measures associated with rehabilitation and participation of people with disabilities. Aside from reiterating the intention to produce a new Base Law for Prevention, Habilitation, Rehabilitation and Participation there was also a suggestion to have a National Plan for Prevention, Habilitation, Rehabilitation and Participation which will be tied in with the Plan to Promote Accessibility. Furthermore, there would be an investment in technical aids and various support mechanisms for people with disabilities in this area. From these observations, it seems that the Government feels more comfortable and confident in pushing forward employment-based provisions and policies when attempting to address the needs of people with disabilities.

From reviewing the legislation there isn't really any mention of children with disabilities. Cash benefits and general provisions are orientated at families with

dependents or children with disabilities. The family is the recipient of the provisions and policies are also orientated at the family. This was clear throughout the interviews and legislation. Furthermore, when referring to sport, the GOP 2004 states that:

Sport is a fundamental right that is constitutionally protected, and should be guaranteed to men and women; children, adolescents, young people and adults; to the population of the continent and autonomous regions; to nationals and internationals; emigrants and immigrants, free citizens and private citizens with liberty within a prison setting; to majorities and minorities; and disabled and non-disabled citizens. (GOP, 2004)

It is interesting that citizenship is only used in conjunction with disability and (indirectly) with criminality. Perhaps this highlights areas where citizenship is contentious. Are prisoners citizens? If not, are they still entitled to do sport? However, by using the term *citizens* with disabilities, it implies that non-citizens are not entitled to participate in sport in the same way in which citizens are. Having a separate category for children and a separate category for 'young people' suggests that there is a difference between children and young people, regardless of whether they have disabilities or not. Furthermore, adolescents and young people are also recognised separately. Could this mean that the term 'young people' may also refer to young adults? If so, policies or provisions orientated at young people could, in fact, be orientated at young adults and not at children as defined by the UNCRC as people up to the age of 18.

The GOP 2004 has suggested various measures orientated at supporting young people with disabilities. These measures include introducing an Integrated Plan for Supporting Young People with Disabilities, whose entitlements include:

- A free youth card
- Incentive for businesses hiring young people with disabilities
- A volunteering programme orientated at supporting young people with disabilities
- Free accommodation at youth hostels for associations providing support for young people with disabilities.

Given the nature of these provisions, it could be said that young people with disabilities are considered to be young adults. This is mainly due to the emphasis on provisions for making employment accessible, a provision that is generally orientated at adults.

Throughout the GOP 2004, 'young people' have been the only mention of a term for someone with disabilities, other than the more general term 'people'. Although the term 'young people', when mentioned, appears to mean those in the later years of childhood, the provisions orientated at young people seem very similar to those aimed at adults. This leads to the belief that 'young people' are in fact 'young adults'. Moreover, other than provisions within education, which are orientated at institutions, there were no proposals directly orientated at children with disabilities. Although this Government has taken the initiative to distinguish between adults and non-adults with disabilities, there is still much to be done regarding children with disabilities.

There were a few other measures included in the GOP 2005-2009, which was produced under the new Socialist Government in 2005. In terms of social services, this government intended to prioritise the creation of aids and services orientated at people with special needs, namely children and young people at risk and people with disabilities. The informant for IR kept mentioning domestic violence and her work within this area. Although this may not seem of relevance to children with disabilities, there was also much emphasis on the effects of domestic violence, and how children and people with disabilities are two of the social groups most likely to be at risk. As a result, it was suggested that sustainable family policies could be developed to tackle this matter. It is important to note that there was no specific mention of children with disabilities, which as highlighted previously can lead to children with disabilities being overlooked.

In terms of disability, policies regarding this area were mainly placed in the section on 'Bigger and Better Policies of Rehabilitation' in the GOP 2005-2009. As stated

before, rehabilitation is a significant, if not the main, focus of disability policy. Within this section the Government highlights that:

The State should offer to its citizens, the possibility of participation in the most diverse spheres of political, economic and social life, creating mechanisms to stop the exclusion of any individual from exercising their rights and duties of citizenship, for presenting a reduction of functions of a physical, psychological, sensorial or intellectual realm. (GOP 2005-2009: IV)

Within this extract there are underlying notions of disability that have been highlighted previously in this thesis. One starts to view the social model of disability emerging through the current policy plans. However, these changes are suggested within the realms of rehabilitation, which suggests a medical approach to disability, rather than a social one. It was said that the areas of action were prevention, habilitation, rehabilitation and participation, and these areas were to be coordinated by the Ministry of Employment and Social Solidarity. Furthermore, with these action areas in mind, it was suggested that there was a need to adapt seven areas in order to improve services and intervention. These include:

1. Social protection – review social repayments based on degrees of disability and vulnerability and improve the status and relationship of the state with relevant NGOs.
2. Employment and Vocational Training – this was the area with most emphasis in this section. It highlighted various measures, similar to those highlighted before, that make the labour market accessible to people with disabilities.
3. Medical Prevention and Rehabilitation – consolidate a model for early childhood education, by establishing a reconcilable policy between the State, Organisations and families, crossing over the areas of education, health and social security, as well as increasing the number of potential responses from specialised public centres of rehabilitation.
4. Accessibility and Communication – affirms the concept of a Universal Design, whilst guaranteeing the inherent value of an inclusive society and reinforcing its development, promoting its adoption in schools' curricula, as well as, creating adequate housing conditions and continue revising insurance systems in the disability field.
5. Culture, Sport and Leisure – make sport accessible through its promotion and removing barriers, and prepare for the Paralympic games in Peking. Provide an incentive for universal access of public cultural materials, promoting the participation of people with disabilities in public spaces, as well as making beaches more accessible.
6. Awareness-raising and Information – develop a national campaign promoting non-discrimination for people with disabilities, raise awareness about chronic and rare illnesses and promote non-discrimination, and, use non-discriminatory concepts and language associated with disability in the production of audiovisual contents, multimedia and also scholastic manuals.

(GOP 2005-2009: IV)

These measures reiterate the measures highlighted in previous GOPs, such as social protection, rehabilitation, employment and vocational training, and sport. This suggests that the implementation of these changes is slow, requiring them to be prioritised on a constant basis. However, this GOP also provided an approach to disability more closely associated with the social model of disability discussed in previous chapters. Most measures were aimed at providing a more integrated and all-encompassing approach to disability, that is targeted at surrounding structures rather than the disabled individual. In fact, measures within field of accessibility have been limited and hardly used in conjunction with inclusion. Furthermore, there has been an increased emphasis on awareness raising and on non-discrimination, which is an area requiring much attention, especially in terms of language use. As has been discussed already in this thesis and will be further elaborated upon below, the conception of disability in Portugal is not only *limited* but *limiting*, due to it being a singular all-encompassing term with derogatory connotations. Addressing this issue would not only improve how disability is viewed but also how it is addressed. Current terminology, such as labelling disabled individuals as ‘deficient’, are imply a more individualised and derogatory approach to the issue of disability. This issue shall be discussed in further detail in Chapter 8.

By suggesting that social, environmental and non-individual barriers need to be removed in order for people with disabilities to enjoy their rights as full citizens, the socialist government is indirectly suggesting that one’s surroundings can also be disabling. However, this notion is only highlighted in the section of the GOP on rehabilitation, a term which has medical connotations, resulting in an interesting synthesis of social and medical approaches to disability in the document.

Throughout the interviews, various informants discussed the introduction of the International Classification for Functioning, Disability and Health for the WHO (ICF or CIF in Portuguese) and its guidelines. In fact, it was a main tool used in classifying and conceptualising disability. If one looks on the WHO’s website, it lists ‘Disability and Rehabilitation’ (DAR) as the only subject in its section on ‘Programmes and Projects’. Furthermore, given the way in which the ICF is

structured, especially when one looks at their checklist, it is inevitable that rehabilitation is the main form of provision advocated by this organisation. This is because there is a heavy emphasis on body function and activity and, although there is a section on activity and participation and even environmental factors, these sections all pertain to the functionality and limits of the body. As a result, when viewing the importance given to rehabilitation in Portugal, perhaps this is due to external influences rather than internal conceptions. If the country looks to the WHO or ICF for guidance in disability policy, then the message these organisations are sending out is that disability equates to rehabilitation. The ICF was given great emphasis within the interviews, and interviewees were very excited about its application. This, however, will be discussed further later on in this chapter.

Regarding Youth and Student Associations (YSAs), the GOP stated it wanted to remodel the Consultative Youth Council and the National Youth Information Web, mainly to fit in with what is set out in the European Youth Information Charter. In addition, the remaining measures are orientated at developing and strengthening legislation regarding the formation, structure and provisions for youth-related associations, including holiday camps. The latter provisions are clearly highlighted in the legislation above for the IPJ. Furthermore, according to the GOP 2005-2009 there would be investment in motivating young people to volunteer, and to mobilise geographically. These measures would also include strengthening provisions and services to enable this transition. In fact, there was a great emphasis on the international dimension of youth policy. Youth tourism, international volunteering, language exchange, information exchange, EU partnerships and events, were some of the various provisions highlighted by the government in this GOP. It seemed that the government was dedicated to strengthening their ties with their EU counterparts and investing in the Europeanisation of their youth policies. Furthermore, there was discussion of how to better exploit the resources available to young people at the EU level, as well as supporting the Portuguese community abroad. This was an initiative that has resonated through to policy and legislation. However, throughout this whole section on youth there was no mention of the section within the young population that has a disability. Similarly, there was hardly any mention of young people and the

provisions for disability within the interviews, suggesting that when I mentioned children with disabilities, although many associated the interviewees considered this category to include those aged up to 18 years of age, young people were possibly perceived as a separate category, especially with regards to disability.

Since the field of Social Security is so diverse, it is no surprise that each of the informants have very different approaches to the issue of disability. Although the informants for Social Action and Regimes did highlight the GOP as a mode of influence within their work, they did not highlight all the provisions within the GOPs as the informant for SNE did. The informant for Regimes tended to brush over issues of social protection and deviate to current legislation, whereas the informant for Social Action tended to highlight the plans associated with private-public partnerships. It was clear that although these two informants seemed to have a stronger identification with the GOPs than the informant for SNE, when it came to policy plans regarding children with disabilities, this was not the case. This is not to say that there is not strong professional identification with the GOPs but, rather, that there is no strong professional identification with the policies regarding children with disabilities.

The informant for Social Action, like the informant for SNRIPD, highlighted the differentiated approaches between governments. Different governments are perceived as producing conflicting and counterproductive policies and measures, resulting in stagnant policy developments. The informant for SNRIPD views their intervention and conflicting with what she feels is her job. However, judging by the GOPs over the years these governments have had similar goals throughout the period analysed. Areas such as sport and leisure, youth initiatives, ECI, integration into the labour market, rehabilitation, social protection, awareness raising and support have been prominent themes throughout. The difference is that within each GOP certain areas appear more developed and coherent. Perhaps there is a need to recognise what the long term goals and priorities are and to work towards them more effectively and coherently. Furthermore, as has transpired within the interviews, different departments have different goals, and although this is a logical structure, each

department seems to overlook the perceived goals and responsibilities of others. However, because there is limited communication and interaction between departments, there is often the assumption amongst civil servants that other departments are dealing with certain issues that fall outside of their own specific remit. This also means that one will not read up on these areas and acquire knowledge about that subject. As a result of this there are areas that will be overlooked because everyone assumes it is someone else's responsibility but nobody is actually taking care of it.

The informant for Regimes has a strong schema associated with what regimes are about and what her department's main priorities are, but showed little empathy with the recipients of policy. This is her main role identification; her professional identity. Therefore, when asked about children with disabilities she talked about areas of social protection, making these measures more transparent and fighting fraud, and any area associated with the needs of children with disabilities were, according to her, either covered by these cash-based provisions or were the responsibility of Social Action or SNRIPD. This is the information she identified within the GOP. The informant for Social Action was concerned with the status and structure of agreements she has with IPSS, she has certain areas which are prioritised and these are stipulated in the GOPs. From the interview, crèches, extra-curricular activities and care homes seemed to be some of the priority areas for Social Action. Any provision other than education seemed to be the responsibility of SNRIPD. SNRIPD seems to be the default organisation that deals with all the policy areas that other departments don't, but these areas are not being articulated. The informant for SNRIPD highlighted social protection, ECI and revising family and child benefits and allowances as being priority areas, which coincides with the function of Regimes. However, as noted by the informant for SNRIPD there is a lack of a global vision of what is needed. Furthermore, provisions are fragmented. There is a variety of different providing bodies and a lack of communication between them. In addition, as has been demonstrated, these providing bodies have differing policy influences, which in turn could add to and result in the fragmented policy outcomes.

5.4 Conclusion

The previous chapter highlighted different international guidelines identified, adopted and implemented by the interviewees. This chapter explored Governmental policy plans produced between 2002 and 2005. In comparing the two, it is clear that not all the international guidelines suggested in the previous chapter have been reflected in these policy documents. Rather, these policy plans seemed to be more inclined to reflecting the EU's 'social' agenda. However, this may reflect the political situation during the time studied, since former Portuguese Prime Minister Durao Barroso became the president of the European Commission in 2004. In addition, the international guidelines highlighted in the previous chapter were not that recent, and may have already been incorporated into national policy. For this reason, they are not emerging in new policy plans, but rather are part of existing policy plans. This question shall be explored further in the following chapter.

In terms of policy plans, the PGs highlighted various policy measures that could be of relevance to children with disabilities. The Barroso and Santana Lopes Governments focussed on updating rehabilitation legislation, improving benefits to children with disabilities and their families, and making sports accessible to people with disabilities. The Socrates Government made similar suggestions to the previous governments, such as improving and updating benefits and focussing on sport and, in addition, looked at developing educational support within schools for pupils with special needs. This has been a pivotal area for the 2005 Socialist government, as has been reflected in the GOP 2005-09. In addition, within the PGs these governments planned to promote the participation of young people with disabilities, and to improve the conditions for the integration of people with disabilities into the labour market, developing the PNAI and de-institutionalisation. In fact, people and young people with disabilities seemed to be mentioned significantly more than children with disabilities. There were also policy plans orientated at children in these PGs that were of relevance to children with disabilities. Policies orientated at children at risk or child care were also mentioned. However, although all these areas can be of particular interest and relevance to children with disabilities, sometimes children

with disabilities may be overlooked as a specific group with particular needs. This is because they do not explicitly fall into that categorisation and their place within those policy areas is not clearly defined. This phenomenon will be explored further in the following chapters.

The GOPs seemed to tell a very different story. Although these plans frequently mentioned young people with disabilities and their integration into the labour market, they also placed emphasis on educational support and aids for children with special needs. In addition, there were also suggested measures orientated at accessibility, social protection and rehabilitation. It seems that the predominant approaches to disability that are starting to emerge are integration and rehabilitation. In fact, if we are to look at the particular entities set up within the civil service that are orientated at people with disabilities, they tend to include either rehabilitation or rehabilitation and integration in their title, suggesting a strong inclination to these principles. As suggested in the previous chapter, these approaches can have their limitations in producing a socially inclusive environment, and do not reflect the approach to disability advocated by the social model of disability.

It is clear that the PGs and GOPs have great influence on the work of senior civil servants, especially the informants for SA, Regimes and SNE. As illustrated above, these particular informants often cited the GOPs and PGs explicitly as sources of influence in their jobs and their policy decision-making. Moreover, in the case the informant for SNE, elements of these documents are present in her responses in terms of the terminology she employed and definitions she provided when questioned on certain aspects of policy. It was also interesting to find that the PGs, which are essentially the governmental manifestos, included a significant amount of EU and international goals and guidelines, such as the Barcelona Agreement. This means that although these informants link their roles to the domestic policy process in terms of the PGs and GOPs, they are also being influenced by, and are indirectly identifying with, international guidelines.

6. Identifying the Context of Policy Decision-Making: National Legislation

6.1 Introduction

The previous chapters have highlighted the different approaches and influences, which international guidelines and governmental policy plans have on policies regarding children with disabilities. The senior level civil servants tended to talk about international guidelines and governmental plans as being amongst the main influences on their job. However, these civil servants also work with national legislation.

I think that implementation reports and international guidelines is a very important area. Primarily, because that's what we have experience with and have a systematic way of applying them. Primarily, because we know the legislation very well. It is a Directorate-General that has a technical/normative role, so we do a lot of legislation, guidelines, etc., and therefore we know the legislation and that helps. (Informant for IR)

As illustrated by the informant for IR, the Directorate-Generals (D-Gs) usually have a technical and normative role in developing and setting out policy as well as defining legislation and national guidelines. However, it is the mid-level civil servants that coordinate and implement policies, which are usually dictated within legislation.

National legislation is the third and final written policy influence identified within the interviews. This chapter explores the main pieces of legislation identified by informants as being of relevance to policies aimed at disabled children. In addition, it will further explore the relationship between this body of legislation, the interviewees, and children with disabilities who are affected by the policies in question. Due to the large quantity of data collected, this chapter has been divided into the two main areas in which the interviewees fall: education and social security.

6.2 National Legislation: Education

Almost all interviewees mentioned legislation within the interview. A few informants stated that all the necessary legislation was in place to meet the needs of children with disabilities and to meet international standards. They did, however, identify that

there were problems or limitations in the implementation of these policy guidelines. Although this may be the case, this section shall explore the extent to which legislation is in fact ‘up-to-date’ and able to respond to the needs and requirements of disabled children and their families. This section shall explore the legislation pertaining to education cited in the interviews and also certain pieces of legislation that, whilst not referred to specifically by the informants, relate to other provisions that were mentioned in the interviews directly.

According to the Portuguese report, the legislative framework within Portugal consists of:

The Education Act (Decree-Law No. 46/86, 14th of October 1986), assumes special education as a specific modality of education, which aims at socio-educational recuperation and integration for individuals with special educational needs caused by physical or mental disability:

- Including such pupils in the regular schooling system, as the educational strategy adopted for pupils with special educational needs, was enshrined in Law No. 9/89, 2nd of May, Law on the Prevention, Rehabilitation and Integration of Disabled Persons;
- Decree-Law No. 35/90, 25th of January, stipulates that students with special educational needs, resulting from physical or mental disabilities, are obliged to attend compulsory schooling;
- Decree-Law No. 190/91, 17th of May, creates the Psychology and Guidance Services (Serviços de Psicologia e Orientação), that identify, evaluate and support e/or psychological and pedagogic guidance to the variety of people involved in the educational process or to support the transition to another training system, collaborating in the drafting of an individual education plan and in the building a life and the projecto educativo de escola. Later, the career of psychologist in the Ministry of Education was created by Decree-Law No. 300/97, 31st of October;
- Decree-Law No. 319/91, 23rd of August, and Implementing Order No. 173/91, 23rd of November, assured the integration of students with special educational needs into regular schools, guided by the following principles: adjustment of measures to be applied to individual educational needs; participation of parents in the educational process; making the school responsible for action taken with regard to these students; individual and flexible educational planning; opening up the school to its community. This legislation is currently being revised;
- Decree-Law No. 301/93, 31st of August, consecrates the obligation of attendance of ensino básico by students with special educational needs;
- Decree-Law No. 115-A/98, 4th of May, which authorises school autonomy, establishing specialised services of educational support, which ensures full school integration for students: (1) Psychology and Guidance Services; (2) the Educational Support Nucleus; (3) other services organised by the school, such as social school services, organisation of study rooms and complementary curricular activities;
- Decree-Law No. 95/97, 23rd of April, was amended by the Joint Order No. 198/99, of 3rd March, defines the legal regime of specialised training of nursery, primary and secondary teachers;
- Joint Order No. 495/02, 7th of May, identifies the organisation of the teaching component for teachers in special education and teaching, as well as teachers working in other educational support at the pre-school and ensino básico levels;

- The Decree-Law No. 20/06, 31st of January, defines the procedures regarding the teacher placement application system, creating the special education recruitment group for the first time. It repeals the Decree-Law N° 35/03, 7th of February. (EURYDICE, 2006/7)

According to this report, the main legislative frameworks for Special Education are present in the pieces of legislation highlighted above. Special Education started in 1989 with prevention, rehabilitation and integration policy identifying that children with disabilities need to be included in schools. In 1990 schooling was made compulsory for children with disabilities and/or additional needs, and psychological and pedagogic support were prioritised in 1991. In the same year there was also the introduction of legislation, in the form of a Decree-Law, making schools responsible for special education and its provision. This Decree-Law shall be discussed in detail later. In 1993, it became compulsory for children with disabilities and/or special needs to attend school. In 1998 schools were given autonomy in establishing educational support for disabled children and in 1997 and later in 1999, different legal regimes were established for specialised educational training. In 2002, legislation concentrated on organising the teaching in schools and later, in 2006, legislative guidelines were established for the recruitment and placement of specialised teachers in schools. It is clear that special and inclusive education is an area that is developing quickly, resulting in the constantly changing legislation in special needs education.

The informant for SNE stated that her priority areas were, ECI (Early Childhood Intervention), quality of education, transition into the labour market and technical aids. However, only the informant for DREL highlighted the pieces of legislation specifically orientated at children with disabilities, which guided her job. Furthermore, she did not highlight any of the legislation cited above as part of legislative framework in which she worked, except for the Decree-law 319/91, which she stated as slightly outdated, and is currently under revision:

There is specific legislation regarding schools. So mainstream schools, as well as CERCIS and other schools... There is legislation that supports these situations. That is a Decree-law 319/91, which is a bit outdated, but anyhow is still in action. And the Joint Order 105/97, that was, let's say remodelled recently last May, that has the number 10 000. I don't know by

heart but I can give it to you. 10 300.... It's basically the same thing with a few alterations. It's those, let's say that is the legislation that will permit everything that has to do with educational support, and then will formalise at ground level, within schools, the organisation of the case of that pupil. So that pupil and this Decree-law, permits adaptations, permits alterations, permits the creation of new curriculum for these children. So let's say that it is that legislation which sustains everything so that the child can go to a mainstream school. So let's say in the case of Joao, the school tried everything and it is on the basis on that of the 319, that it tried everything to keep him there. Let's say that there are adaptations in terms of the curriculum, in terms of the materials... a series of adaptations, and alterations, only when it is no longer possible, then we direct and support them through schools. Even in the school, so school or CERCI, has to organise the student's case, organise the access to education, also framed in that legislation. So in terms of social policy, that legislation is more concerned with the issue of learning. Although in the Special Education Institutions, in CERCIS, there is a social worker. So, they have and pay a percentage to have a social worker, and this helps manage the special situations of the family and pupil. In terms of the mainstream school, this person, this technician, doesn't exist.

(Informant for DREL)

This informant identified her job as being to provide support to institutions catering for the education of children with Special Educational Needs. In association with this role and provision, she highlighted two pieces of legislation – the Decree-law 319/91 and the Joint Order 105/97 – that have now been replaced by the Implementing Order 10854/2005. These pieces of legislation are the guidelines for all public and private education institutions at primary and secondary level, covering the provision of support for pupils with special needs by these institutions. This also includes Cooperatives for the Education and Rehabilitation of Maladjusted Children (CERCIS) which are a range of educational institutions for people with special needs, which are part of FENACERCI. When interviewed the Vice-President of FENACERCI, he stated that these policies and legislation are taken into account in the structure of his institution and that they are modelled accordingly. The Decree-Law 319/91, according to the EURYDICE report, is used in association with the Dispatch n. 173/91. According to the informant for DREL it is used in association with the Implementing Order 10854/2005, which replaced the Joint Order 105/97. If this is the case, then it would appear that Portugal, in terms of fulfilling international standards, is not completely up to date with its legislation. In looking at this Decree-law, it states:

It was considered in the present diploma, the evolution of concepts resulting from the development of experiences of integration, we emphasise here:

The substitution of classifications in different categories, based on medical decisions, for the concept of 'students with special education needs', based on pedagogical criteria

The growing responsibility of mainstream schools for the problems of pupils with disabilities and learning difficulties.

The opening of schools for pupils with special educational needs, for the aim of a 'school for all'.

An explicit acknowledgement of the parents roles in the child's schooling.

To guarantee, finally, a range of measures whose application based on the principle that the education of pupils with special educational needs should be processed in the least restrictive manner, so that each of the measures should be adopted when it is deemed indispensable for achieving the defined educational objectives. -

(Decree-Law n. 319/91: Preamble)

Although it was suggested above that this Decree-law to be outdated it does provide a more inclusive and social approach towards disability. It places the responsibility on schools to provide an inclusive educational setting, and aims to make schools accessible to all. Within this Decree-law the measures to be allocated were:

- Special equipments of compensation
- Material adaptations
- Curricular adaptations
- Special matriculation conditions
- Special attendance conditions
- Special evaluation conditions
- Adequate organisation of classes and years
- Increase pedagogical support
- Special Education

(Decree-Law n. 319/91: 2)

Although these provisions seem to have an inclusive approach, this legislation is quite limited. It only states the entitlements of pupils with special needs, but not how to go about structuring this provision or the specific details of how this might be achieved. It is also important to note that there was no specialist unit for special education within schools, leaving it to the discretion of schools that were not specialised in this area. As highlighted above, special educational boards have just been introduced within schools. Prior to that, specialised teachers were placed temporarily in different schools on a yearly basis and, as mentioned by the informant for SNE there was an underlying instability in special education provision. Although the DREL was coordinating and supporting the distribution of special education measures, it was clear that a more integrated approach was needed within schools.

Having now developed a more integrated approach, then legislation such as that above has to be adapted to:

Promote and develop practices that manage to obtain clear and sustainable developments in the organisation and management of educational resources, quality of learning, with the aim of offering various opportunities to all the citizens, is the central political objective of the Government. It is only possible to go forward in the path of inclusion and equality of opportunities, protecting and valuing the public service of education and public education open to all. The schools are the centre of the educational system. They should be structured in a coherent web of educational and vocational resources in all the territory. We urge to consolidate the dynamics of school clusters of primary education and organise the educational support in accordance with the new reality and according to a set of guiding principles, namely:

Centralising in the clusters and remaining schools the diverse necessary interventions for the educational success of all children and young people, whilst aiming to obtain a greater flexibility of principles and norms defined at national level, in order to be able to contemplate the variety of situations that characterise the educational framework and the individual dynamics of schools and school clusters, as well as the geographical and social contacts in which they are placed.

Alter the way of conceiving and organising the system and educational resources, so as to centralise them in the general public's interest, and specifically, in the interest of the pupils and their families. (Order n. 10856/2005: Preamble)

It is clear from this order, that it contains a more comprehensive structure and approach to what special education is supposed to be in Portugal. Whereas the Decree-Law n. 319/91 was revolutionary in highlighting the rights of children with additional or special needs in schools and in taking an approach more closely associated with the social model of disability, it is Order n. 10856/2005 elaborates on how this should be achieved within Portugal. Special Needs Education is a recent development and, consequently, it is constantly developing and changing. Therefore, it is of no surprise that while this initiative develops, policies and legislation regarding it are constantly being developed and refined and many soon after become outdated. This is illustrated by the example above with the example of the Decree-Law n. 319/91. This recent order provides the guidelines that are adopted not only by state institutions, but also private institutions of education. It highlights the process by which provisions within the area of education should be allocated. It also adds to a previous joint-order that was perceived as needing to be given greater depth, although if you explore both documents, as stated above, the differences are minimal. According to this piece of legislation there are various tiers to the process involved in claiming educational support. It starts with the teacher who identifies the needs of the pupil. She then expresses the need for support to the relevant administrative body

within the school. This administrative body then submits this to the coordination team of educational support. There will then be an evaluation of the student to view what is the specific support that she/he requires and what measures are the most appropriate way of responding to these needs. A report is produced detailing:

- a. The number of students that need new resources or specific adaptations to existing resources
- b. Characteristics of the pedagogical project that substantiates the needs of a teacher to fulfil the function of educational support
- c. The dimensions of the secondary cluster/school in terms of the number of students and classes
- d. The geographic location of the school(s)

These reports are then submitted to the Regional Directorate for Education. The Regional Directorate, through these coordinating bodies, grants the support it believes is needed, using guidelines set by the Directorate-General for Innovation and Curricular development (DGIDC). The DGIDC in turn produces a report with the balance of measures for educational support and proposals for future intervention, whilst the Regional Directorate will also produce reports on these respective areas of intervention. This process was identified by these informants within the interviews. It is important to note, however, that the informant for SNE also stated that schools were given lists of resources that are available and that schools had to ask for those resources. In addition she stated that everyone always wants more resources and that 'too many resources can be perverse.' Whether it is perverse or not, this approach suggests a certain rigidity in terms of how support is allocated. Firstly, it seems that the level of resources available is already predetermined and schools have to select the ones most fitting their needs from what is available. Secondly, there seems to be a limit on what resources are given to any institution.

When reviewing these pieces of legislation the limitations become apparent. Above all, they came about in the time period prior to the establishment of integrated special

education boards in schools. Secondly, and more importantly, by making schools accountable for making education accessible to all, it directs policy at the institution rather than the individual which, as has been discussed in previous chapters, is often the approach suggested by those advocating pro-inclusion measures (see Allan, 2006). It is mainly teachers who are involved in the identification and implementation of educational aids. This may result in a conflict of needs between the political actors involved, such as teachers, the school's administrative bodies, coordinating bodies and the regional directorates. Whilst these issues are being addressed and dealt with, the actual needs of the pupil requiring support may be overlooked due to the importance given to the needs of the support network surrounding her/him. In addition, the fact that specialised teachers are only placed in schools temporarily is a significant drawback to this process, due to the lack of continuity and the varying perceptions and needs of each teacher.

In addition, this piece of legislation also re-emphasises the conception of citizenship being to the preserve of working adults. As stated above in the preamble of Order 10856/2005, education has the aim of providing opportunities to citizens, or making citizens more employable. It does not state that education is granted to all citizens, or that all citizens have the right to education. This implies that those within education are not necessarily conceived of as citizens. Nonetheless, the above legislation on special education confirms, if not mimics, guidelines set out by the Standard Rules. It allocates responsibility to educational boards for special needs education, it involves the community, and it involves parents in decision-making. Furthermore, by having measures such as ECI they also target pre-school children, which was a priority area for the Standard Rules. If the UN is advocating an integration/normalisation model, then is Portugal to blame in shortfalls?

Flexibility has been a key concept within this area, and a term that has been used exhaustively both nationally and internationally. The pieces of legislation highlighted above allow and encourage flexibility in what support is allocated to individuals by making the provision of support contextual, and suggesting a more pluralist approach to educational support. There is no standard approach to be taken, but rather a

collection of contextual responses to the perceived needs of each case. This flexibility has also been highlighted and emphasised in the interviews with the informant for DREL and FENACERCI. The informant for FENACERCI identified ECI and Special Education as the two priority areas regarding children with disabilities. With regards to special education he stated:

Special education is an area that has the priority of being inclusive. The children with mental disabilities should always be with other children in mainstream education, but should also be surrounded by a compilation of special education measures. That's where our cooperatives are situated. Children with mental disabilities that are so, so severe are sent to us. The schools don't have the means to take them in. The children that, I don't know... that not only do not communicate, to those not having control of the sphincter, very severe problems that can't be cared for in mainstream settings. So they are sent to special schools, which is where our organisations exist. Currently, our organisations, our cooperatives do or have cooperation projects with mainstream schools. So, besides from having those clients that are in a boarding regime, we also do cooperation projects with children that have disabilities, that although they attend and have support in mainstream schools, they still need complementary support that is then given by our organisations. So these are the two areas, let's say the area of ECI and the of Special Education are the measures that are taken into account in our organisation. Then within these areas there is a domain for action. A domain that is extremely important incorporating a variety of domains, like for example the domain of communication, we have children with mental disabilities that have a severe disability in terms of communication. Communication as you know is the key of all processes that can affect inclusion and exclusion. Therefore we recognise a domain for action is the domain of augmentative or alternative communication. Exactly. For example sign language for children who cannot discuss in verbal or written form. So that is another domain which we find is a priority. And if we are to look at transversal domains, we have the domain of sport, where we have to adjust activities to ones capabilities and abilities. Which means we have to do an effort in our organisations to do cultural and sports initiatives adjusted to those children. (Informant for FENACERCI)

The informant for FENACERCI stated that his institution would not only adapt to current legislation, but would also seek to provide the services needed which were not currently available in that area. He elaborated that they need to have legislative guidelines in place in order to secure funding. Although he identified himself as being independent from the government and the civil service, he touched upon all the areas mentioned within legislation and the GOPs. The informant for SNE mentioned that sign language and communication was a priority area in terms of policies oriented at children with disabilities, implying a broad conceptualisation of disability to include those with speech and hearing impairments. The informant for FENACERCI, by contrast, spoke exclusively about children with mental disabilities. It seems that because he is providing education for children with severe disabilities,

he seems to identify that these children have mental disabilities. Perhaps because there is no overarching term for learning difficulties in Portuguese, the interviewee has adopted the use the term mental disabilities to refer to a variety of often unrelated impairments. As a result of this, he seems to group hearing impairments and sphincter control, neither of which are mental disabilities, under this same umbrella. Nonetheless, this informant managed to highlight all the policy priority areas that were identified by the civil servants, especially the informant for SNE. The need to securing funding was also quite prominent, as it defines the priority areas for the organisation. In addition, the aim of FENACERCI was to meet the needs of the public, and hence it would also structure services according to the most obvious needs. However, as suggested above, these needs are already predefined in existing legislation. The extent to which this flexibility is successful in meeting the needs of the public, remains to be discussed. The informant for FENACERCI had stated that support from the government alone is not enough, limiting its ability to provide an effective, all-encompassing service.

Although the informants within education did not mention legislation regarding ECI, their views of its purpose are confirmed by the existing legislation. As stated below:

Early Childhood Intervention is an integrated support measure, centred on the child and the family, mediating actions of a preventative and habilitative nature, mainly in the area of education, health and social action, whilst envisaging:

- a. Assuring the facilitating conditions of development of the child with disabilities or at risk of a serious delay of development.
- b. Provide potential to improve family interactions.
- c. Reinforce the family competencies as a support to their progressive capabilities and autonomy when facing the problematic of disability. (Joint Order 891/99)

This Joint Order was published in 1999 and is, at the time of writing, under review. However, since it is the only existing legislative guideline on the matter of ECI, and it is the one adopted by all agencies in question. Interestingly, it too was not mentioned in the EURYDICE report. In fact, ECI has been highlighted separately in the European Agency and in Portuguese policies. Special and inclusive education on the one hand and ECI on the other are seen as separate and distinct measures. As stated above, ECI is aimed at preparing and equipping the family with the skills needed to care for a child with disabilities. ECI is not principally concerned with

meeting the needs of children, but is more about meeting the needs of parents in terms of how to care for their child. This clearly reflects the familialist characteristic of the Portuguese welfare state. ECI is available for children aged from 0-6 years, and when asked what happens after that age, the majority of informants who touched upon this matter, admitted that the restriction of care to children aged under 6 was a clear limitation in the provisions available. However, if the aim is to prepare parents for their child's upbringing rather than to cater for the needs of the child themselves then this piece of legislation fits that purpose. If the responsibility for the child's well being resides with his parents, it can be argued, the latter will be well equipped to meet these needs having gained the necessary skills and expertise during the first 6 years of the child's life.

The limitation of this policy arises when one takes the question of children's rights and disability rights on board. This is because the responsibility for the disability is placed on the family, rather than the state or on society more generally. This will result in an individual/familial approach to disability, where the individual and her/his family is responsible for their disability and condition. Clearly, this can be quite limiting for both the child and their family. However, this limitation was not necessarily noted within the context of education policy, but came to the fore mainly within the interview conducted with the informant for SNE, as provisions are allocated to schools and children throughout their educational lifespan. This lifespan usually extends to the end of childhood, meaning that, in this case, there should be a guaranteed interaction between the state, the child and the family.

In addition to ECI, the informant for SNE highlighted that technical aids and support were also mentioned as a provision within education. Between 2000-2005, legislation regarding technical aids was modified on almost a yearly basis, with the purpose of clarifying the conceptualization of 'persons with disabilities' and 'technical help'. This legislation also established the total amount of resources available and define the procedures for the allocation of technical aids. Between 2002 and 2005, there were two such changes: Order 24764/2003 and the Order 26390/2004. Order 24764/2003 states that:

It is considered someone who has a disability if they, for cause of loss or anomaly, congenital or acquired, of psychological, intellectual, anatomical or physiological structure or function, that are susceptible to the provocation of restrictions of capacities, can be considered in a disadvantaged situation for the exercise of activities considered normal, taking into the account the age, gender and dominating socio-economical factors.

Technical aids, including those in current new technologies, are destined to compensate the disability or to lessen the consequences and permit the exercise everyday activities and participate in school, professional and social life. (Order 24764/2003)

The approach to disability in Portugal is quite consistent throughout the legislation and also the interview data collected. It seems to be impossible to discuss a person with disabilities without mentioning the disability or impairment. However, the approach taken to disability in general is different. Disability is usually discussed with regard to impairment and normality. You are disabled if you have an impairment and cannot do 'normal' activities. As a result, technical aids are aimed at allowing people to be 'normal' and to undertake 'everyday' activities: to participate in school or the labour market and to have social lives. Order 24764/2003 also lists the agencies that are supposed to assess which technical aids should be provided. All the agencies listed are either health centres, hospitals or rehabilitation centres, providing a highly medicalised approach to disability. This conception of disability is reinforced by the fact that technical aids target the impairment and not society. The idea of normality is a socially constructed concept that is open to a myriad of conflicting interpretations. The assumption that there is a universally accepted concept of normality against which so-called abnormalities can be defined is highly contentious. However, by structuring policies to aim for this mythical 'normality,' they will never be able to achieve their objective.

In 2004 there was a joint dispatch that put together a working group with the objective of elaborating and proposing legal measures for technical support. Later on that year there was a new Order 26390/2004 published in the Diary of the Republic. The Order stated:

In terms of article 2 of Law 38/2004, it is considered someone to have a disability if for cause of loss or anomaly, congenital or acquired, of function or body structure, including

psychological, intellectual, anatomical or physiological structure or function, that present susceptible specific difficulties, in conjunction with other factors, as a means to limit or provide difficulty to activities and participation on the basis of equality with other people. (Order 26390/2004)

This order offered similar approaches to technical aids to be administered through the same agencies as those stated in the previous order. However, the conception of disability contained in Order 26390/2004 seems slightly different. In the new order, the perception of disability is based on impairment and equality of status rather than an idea of normality and the provision of equality of opportunity. This change in aims was highlighted by the informant for SNE. It seems this is an area that is also in rapid transition. In addition, there were other pieces of legislation on technical aids that were specifically orientated at people with visual impairments who have guide dogs, and others related to the provision of colostomy bags, prosthetics and orthotics, as well as, access to emergency services. In 2004, there was a significant initiative that aimed at making IT accessible.

Decree 1354/2004 aimed at the inclusion of people with disabilities in the digital world, in order that they would be better able to access information and increase their participation. This is an important breakthrough as the extent to which one can participate and be included in society, as well as fulfilling one's rights, very much depends on the extent to which one is informed about the type of support and assistance which is available from the state. The informant for SNE, like the informant for SNRIPD, said that this is an area under review, and with a new Secretary of State for Rehabilitation within the Socialist Government, perhaps this is an indication that disability related policy is due for a long awaited overhaul.

In SNRIPD, the priority areas at the moment is accessibility and technical aids is an area. They are 2 priority areas, because they are areas... This here in terms of this organisation, isn't it? Because they are 2 areas that are basically... While the other areas related to the question of education and its provisions, the said allowances, employment, are fundamental areas, obviously for a person with disabilities, but they have their appropriate sectors. Isn't it? Whilst accessibilities and technical aids are clearly transversal. It's no one's land, so to speak. Or it's everyone's land but there isn't a governmental sector that has a Ministry to start with, that assumes it as particularly theirs.

(Informant for SNRIPD)

The informant for SNRIPD also highlighted that for this organisation accessibility and technical aids are areas of great importance. This is mainly because these issues cover a wide range of areas and are thus hard to manage and coordinate effectively. According to article 2 of Decree-Law n. 123/97 technical norms regarding accessibility should be applied to all public buildings and institutions. However, private constructions are exempt from this law, as well as buildings that are already in existence. This legislation is slightly discriminatory as it does not push for all buildings and infrastructures to be accessible and allows for many exceptions to the rule. It does, however, push for all buildings to advertise clearly whether they are accessible or not and for those buildings which are accessible to highlight their accessibility. The informant for SNRIPD stated that no one had previously even contemplated accessibility as being a policy priority and that it was now slowly developing and becoming a more mainstream policy concern. The legislation above has been subject to change. Hopefully, it shall incorporate a more inclusive approach.

The priority areas that affect me most are ECI, Education although my colleague has taken over some of my work, a Work Group on de-institutionalisation for the Council of Europe and the ICF.

(Informant for SNRIPD)

Although the informant for SNRIPD finds herself within the Social Security umbrella, she tended to identify more with the Ministry of Education and kept mentioning her links to education policy. Perhaps this is because the Ministry of Education has a department which specialises in special education, whose role is mainly to work with issues concerning children and young people with disabilities, whereas Social Security has no such specialist department. Alternatively, this concern with education may be because a high proportion of the needs of children and young people with disabilities are met within the educational setting. Nonetheless, the informant for SNRIPD seemed to share an affinity with education, and the priorities highlighted by the informant for SNE.

One of the key areas SNRIPD covers is rehabilitation. All entities aimed at people with disabilities usually have rehabilitation in their title. The Base-Law for

Rehabilitation was set up in 1989 and as stated above has not yet been amended. It aims at promoting and guaranteeing the rights written in the Portuguese Constitution relating to the prevention of disability, the treatment, rehabilitation and comparative equal opportunities of persons with disabilities. There have been plans to change this legislation, mainly in order to speed up support and integration for people with disabilities. The Base Law for Rehabilitation states, when defining a person with disability, that:

a person with disability is one who through a congenital, or acquired, loss or anomaly of ones psychological, intellectual, physiological and anatomic function, which makes one susceptible to having their capabilities restricted and can be considered disadvantaged when exercising activities considered normal, taking into account age, gender and socio-cultural factors. (Law 89/9: 2)

Interestingly, although the Order 26390/2004 stated that it was based on the above law, the previous order in 2003 had demonstrated an understanding of disability more closely aligned with that found in the Base Law. This law reaffirms the concepts of impairment and normality. It suggests that disability is a result of impairment and not the social barriers preventing a person from exercising their daily activity. Furthermore, there is an emphasis on normality, suggesting that there is such a thing and that there is a consensus on what are normal activities.

Stalker et al. (1999) argue that the concept of normality can be oppressive as it pushes people to strive to be 'normal' instead of just being themselves. Even if there is a suggestion for tackling social barriers within this law, which there is, those provisions are overshadowed by the conception of disability which informs it, since impairment will always be seen as the underlying cause of disability. Interestingly, the difference in definition between rehabilitation legislation and technical aids, is that the law above mentions socio-cultural factors when regarding rehabilitation and socio-economic factors when regarding technical aids. This is perhaps due to the fact that the high cost of technical aids can be limiting and disabling, whereas socio-cultural factors are identified as disabling barriers within the context of rehabilitation. Unfortunately, this is not the change suggested by this GOP. However there was a suggestion to approve a Base Law for Prevention, Habilitation,

Rehabilitation and Participation of the Person with Disabilities. This Base-Law would aim to:

- Consecrate forms of support for families of people with disabilities, envisioning their full participation in society
- Create a Program for Inclusion and Development (CNPJ, 2008)

Before exploring the Base-Law, it is important to explore the nature of these aims. The first aim starts by stating that provisions shall be orientated at the families of people with disabilities, and ends by promoting full participation in society. This statement highlights that this change in legislation envisions the full participation of families with people with disabilities within society rather than the full participation of the person with disabilities her/himself. Furthermore, a Programme for Inclusion and Development specific to disability was to be created. On the one hand, this could be effective as it only targets the issues regarding people with disabilities and hence it is more focussed on tackling issues in that area. On the other hand, there is already the PNAI, and constructing another programme similar to that one, but concerned specifically to disability, may lead to confusion and, if they are seen as needing their own programme, the further segregation and distancing of persons with disabilities and the increasing stigmatisation of disabled people as ‘different’.

There was also a Base Law for Rehabilitation which later developed into the Base Law for Prevention, Habilitation, Rehabilitation and Participation of the Person with Disabilities, and these are major policies and legislation regarding people with disabilities. According to the Base Law for Rehabilitation:

1. Rehabilitation is a global and continuous process destined to correct disability and to conserve, develop or re-establish the aptitudes and capacities of the person for exercising activities which are considered ‘normal’
2. The process of rehabilitation involves the counselling and individual and familial orientation, presupposing the cooperation of professionals to the various sectoral levels and the involvement of the community. (Law 89/9:3)

This concept of rehabilitation was later developed and modernised in the Base Law for Prevention, Habilitation, Rehabilitation and Participation of the Person with

Disabilities. Although this legislation does not define rehabilitation as such, it emphasises the measures associated with rehabilitation.

Habilitation and rehabilitation constitute measures, namely within employment, work and training, consumption, social security, health, habitation and urbanisation, transportation, education, culture and science, fiscal system, sport and extracurricular activities, whilst envisaging the learning and development of aptitudes, autonomy and quality of life of people with disability. (Law 38/2004: 26)

The Law 89/9 took a somewhat outdated approach to disability by viewing rehabilitation as a process of ‘normalisation’. Furthermore, measures within this area were to be orientated primarily at the individual or their family, with the aid of professionals and the wider community. Rather than focussing on who rehabilitation targets, the Law 38/2004 highlights the areas that rehabilitation targets. Moreover, it takes a differentiated approach to rehabilitation in identifying different areas of intervention regarding disability. What we are seeing here is probably a transition in the conceptualisation of disability from the individual/medical model to an approach based more on the social model of disability. Participation, autonomy, non-discrimination and citizenship are some of the areas mentioned within the recent legislation, highlighting a more social model based understanding of disability. However, it seems that rehabilitation is still seen as the main response to approach these areas, which still resonates with elements of the individual model in which impairment is still seen as the basis of disability. Furthermore, the conceptualisation and definition of rehabilitation, and who it is orientated at, has not yet been updated within legislation. This could limit the implementation of changes in legislation. The perception of implementation is not changing, although it is targeted at more areas.

In terms of ‘equality,’ there were various measures highlighted within the area of participation and rehabilitation. One of the measures taken was to develop the Base Law for Prevention, Habilitation, Rehabilitation and Participation of the Person with Disabilities. Other measures in this area included making transportation accessible, managing the outcomes of the EYPD, preparing for the Athens Paralympics in 2004, developing policies regarding disability and making information more available.

With regard to work, employment and vocational training, there was a wider variation of measures associated with rehabilitation and participation of people with disabilities. Aside from reiterating the intention to produce a new Base Law for prevention, habilitation, rehabilitation and participation there was also a suggestion to have a National Plan for prevention, habilitation, rehabilitation and participation which will be tied in with the Plan to Promote Accessibility. Furthermore, there will be an investment in technical aids and various means of support for people with disabilities in this area. From these observations, it seems the government feels more comfortable and confident in pushing forward employment-based provisions and policies when regarding people with disabilities than any other disability-related area.

It seems that legislation regarding children with disabilities can be quite contradictory in nature. On the one hand, there is a push for a more social model approach to disability, aiming to make society accessible and inclusive. On the other hand, outdated, medicalised approaches to disability remain within legislation that do not correlate with progressive policies emanating from the social model approach. Until this inconsistency is addressed, it will result in policies being disjointed and limited. There are a lot of plans within the area education to address these issues. However, the extent to which these plans translate into concrete outcomes remains to be seen. As stated in various interviews, many plans such as these often are put on the back burner when there is a change in government, resulting in a backlog of urgent changes that can take years to be addressed.

In the case of education, there are certain inconsistencies in the approach taken to policy, since disability and provisions are not viewed in the same light throughout the policy process and the conception of each of these elements does not compliment the other. Furthermore, making families and schools accountable for the child's disability and structuring provisions accordingly could result in the child's actual needs being overlooked. This is because the family's or the school's needs with regard to the child, such as organising managing the class, would be brought to the forefront, clouding what are actually the child's needs. As highlighted by Fulcher's

(1989) studies on education policy surrounding disability, she found that professional expediency played a major role in policy decision-making, where different professionals would tend to push for what was in their best interests. In addition, for civil servants who do not work with or keep up to date with international guidelines, having outdated legislation means that they will be exercising these principles on a constant basis. This means that their schematic framework in this context will be strong and hard to penetrate with new conceptions and perspectives on disability and the provisions to cope with the needs of disabled persons. Moreover, these schemas will get stronger with practice. This, too, will result in a differentiation in knowledge and understanding between top level civil servants and intermediate to lower level civil servants, resulting in inconsistencies in the policy process.

One could say that top level civil servants and the government need to identify this phenomenon and invest in training to address these problems, closing the gap in knowledge that exists between the tiers of the civil service. However, the informant for DREL did state that as part of her job she is reviewed on a constant basis. These reviews usually result in the review panel suggesting training courses to develop her skills to meet the demands of her job. She stated, however, that she tries to keep up to date with new technologies and new measures within the area of education. Conversely, one could argue that Portugal, by focusing on guidelines from the UN and the EU, are left with policies orientated at integration and employment. As a result, if training is orientated at these priorities, then disability policy will remain stagnant. Unfortunately, Portugal has not yet been influenced sufficiently by a disability movement. Furthermore, as stated by the informant of FENACERCI, Portugal does not currently have the financial means to fully integrate these approaches. Having explored legislative guidelines for education, the following section shall explore legislation within social security.

6.3 National Legislation: Social Security

The informant for IR placed heavy emphasis on the availability of information on the internet. She highlighted that her department made all their information available on the internet for others to use and keep themselves informed about developments in

this area. According to the website for social security, the main pieces of legislation that regard children and young people with disabilities are the:

- Regulatory Decree 14/81 – Special Education
- Decree-Law 133-B/97 and Decree-Law 341/99 – Social protection for family obligations.
- Regulatory Decree 24-A/97 and Decree-Law 15/99 – Family Subsidies
- Decree-Law 208/2001 - Reinforced social protection to disadvantaged citizens
- Decree-Law 250/2001 – Family Allowances
- Decree-Law 133-C/97 and 341/99 – Family Allowances

The only informant who mentioned specific pieces of legislation in her interview was the informant for Regimes. The Decree-Law 133-B, mentioned by this interviewee, defines the protection for family responsibilities under the umbrella of social security, which is based on the general regime and the regime for social protection. In terms of children and young people with disabilities, it states that family subsidies will receive a bonus and shall be allocated to:

- a) People under the age of 24 needing individualised pedagogical support and/or specific therapies, adapted to the nature and characteristics of the disability one possesses, as a means to prevent its aggravation, to annul or reduce its effects and permit complete social integration.
- b) Frequent specialised establishments of rehabilitation. (Decree-Law 133-B/97)

In addition, as will be discussed further in Chapter 8, families with people with disabilities that are unemployed are entitled to a lifelong subsidy. As discussed, the approach to education for children with disabilities was based on integration. Within this legislation, this notion of integration is once again evident. Subsidies are allocated in order to ease integration, and are aimed at correcting impairment. Again, this notion reflects the principles found within the outdated, individualistic WHO principles suggested by Barnes (2003). Following the Decree-Law 133-B/97, the Decree-Law 133-C/97 highlighted protection measures for children and young people with disabilities. According to this law:

- 1 - Children and young people with disabilities have the right to a bonus on the family subsidy if they are frequenting an establishment of special education, in accordance with the general regime of social security.
- 2 – Those entitled to this bonus because of disability, can opt to have a social pension that is verified by the required conditions for such (Decree- Law 133-C/97)

This piece of legislation states that families with children and young people who are receiving special education have the right to receive an additional amount to that of the regular family subsidy. It seems that these cash benefits are allocated on the basis of services that are being used, orientating provisions at both the family and the micro (services) level. This is a very similar decentralised approach to that taken in the field of education policy. In addition, provisions are given on the basis that one is actually using a service or provision. This is beneficial since it guarantees that the allocated cash benefits are used for the purposes for which they are intended. However, it could also be a disadvantage since the state is dictating and controlling the choice of provision one has. One is only entitled to this benefit if one is attending an institution that provides special education, which could force one to attend such an institution in order to secure these benefits.

As previously highlighted, the UNCRC does state that children should have the right to education. In addition the Standard Rules stated that integration should be promoted. However, the legislation discussed above suggests that education is compulsory or an obligation rather than a right.

In terms of Special Education, the social security website highlights a different piece of legislation to that of education. The Regulatory Decree 14/81 states that:

It is conferred the right of subsidy to children and young people of an age that does not exceed 24 years, who possess a confirmed permanent reduction of physical, motor, organic, sensorial and intellectual capacity, who in addition are defined solely as disabled, only for motive of this disability, they find themselves in:

- a) Attending establishments for special education that require a monthly payment
- b) That need to enter mainstream schools, after having attended special schools, that have not or been able to make the transition into official establishments, or, having made the transition, need individual support or a specialised teacher
- c) Having a disability that, although not requiring special schooling, need individual support or a specialised teacher
- d) Attend a mainstream crèche or kindergarten as a means to overcome the disability and rapidly achieve social integration. (Regulatory Decree 14/81)

Within Social Security, provisions for special education are allocated in the form of a cash benefit or allowance. The above decree states that children who have a disability and require special education and/or support are entitled to a subsidy to support that provision. This support is available to those attending establishments such as schools and crèches that are recognised by the ministry of education, and is either allocated to the individual directly or as a concession when paying fees at these institutions. Note that it is only available to children and young people within special schools that are paying a monthly rate, as well as those requiring support in mainstream schools, and children attending mainstream crèches and kindergarten. However, this regulatory decree states that when regarding children within mainstream crèches and kindergartens, subsidies are aimed at overcoming disability and achieving social integration. Within other contexts, subsidies are aimed at supporting fee payments or supporting (but not necessarily overcoming) the consequences of disability. It is important to note that children with disabilities between 0-6 years of age are entitled to early childhood intervention (ECI).

As discussed above, ECI takes a preventative and habilitative approach to disability. These approaches tend to be orientated at 'curing' disability or, rather, encouraging normalisation; a process which is synonymous with integration. The aim is to adapt the child to their settings, rather than adapting the settings to the child and/or the person with a disability. As a result, the approach to children with disabilities in mainstream crèches and kindergartens is consistent with other policies for that age range. However, social integration is not mentioned with regard to children and young people within schools. At this stage provisions are orientated at aiding the educational process, and although these measures are indirectly associated with integration, they are not emphasised as such. Children without disabilities of a similar age, are not socially integrated in society, nor are they encouraged to be socially integrated. In fact, if one looks at policy and legislation, this integrated, if not inclusive, approach arises only when one becomes a young person, or a person of working age.

The focus on children with disabilities between the ages of 0-6 has been prominent throughout the interviews, especially in the area of social action. This is due to the focus on ECI as a measure for children with disabilities, which seems to overshadow all other provisions and/or initiatives. In fact, when asked what happens between the ages of 6 and 24, most respondents did not have an answer, and one of the informants for ISS stated that it was a gap that had been noted and was being addressed. Nonetheless, the specialist on children's issues in the ISS mentioned additional areas of intervention.

We have an area that has been prioritised, which has been the area with the problematic of children at risk. So it is the homeless, the drug-users, and in the past few years there has in fact been a great relevance. And then, the area I know better is the area of infancy and youth. So here we incorporate everything, the situation of risk, situation with the family, the situation of danger, that are also in the area of disability. There is also the question of dependency and elderly, with the onset of old age in the population, this area is prioritised. - (Children's Specialist)

Similarly to the informant for DREL, the interviewees from the ISS stated that they did not have a direct interaction with the public, but rather with those institutions that do interact with the public. It is important to note that this interviewee started this statement on what her priorities were with the phrase, 'what are our vulnerable groups?' This indicates that priorities are based on areas or people that are deemed vulnerable.

The specialist on children's issues identified children at risk as one of her main policy priority areas. It is important to note that at the time of the interviews, there were various reported cases of abuse and neglect that resulted in the death of children. These cases were highly publicised in the media. The children's specialist was very involved in the area of children at risk and, from the frequency with which she referred to this issue, it seemed that at the time it was her main priority area. She also highlighted that children with disabilities can also be at risk. Interestingly, when contacting the *Comissão Nacional de Protecção das Crianças e Jovens em Risco* (National Commission for Protecting Children and Young People at Risk - CNPCJR²) to talk about the protection of children with disabilities, the receptionist

² Portuguese abbreviation

stated that it was not an organisation for the disabled. This shows that although senior civil servants and members of the CNPCJR, such as those interviewed, may be aware of the risks presented to children with disabilities, one first has to get past the receptionist who may be unaware of the risks confronted by children with disabilities. The perception of this receptionist could be a barrier for children with disabilities in attaining their basic human rights. Nonetheless the Law n. 147/99 for protection of children and young people in danger takes a rights based approach and promotes wellbeing in ones development. According to article 3 in this law:

1 – Intervention to promote the rights and protection of children and young people in danger takes place when the parents, legal guardian or representative put their safety, health, training, education or development in danger, or when that danger results in an action or omission of a third party or the actual child or young person, in that that no one opposes it or removes this danger.

2 – As child or young person that is in danger is considered to be found in one of the following situations:

- a) Is abandoned and lives on his/her own
- b) Suffers from physical or psychological abuse or is victim of sexual abuse
- c) Does not receive the adequate care or affection for their age and personal circumstance
- d) Is obliged to do excessive or inadequate activities or work for ones age, dignity and personal situation or prejudicial to ones training or development
- e) Is subject to, directly or indirectly, behaviours that severely affect their safety or emotional stability
- f) Undertakes behaviours or takes part in activities or intakes substances that severely affect their health, safety, training, education or development, without the parents, legal guardian or representative adequately opposing or removing them from the situation. (Law n. 147/99: 3)

Although discussion of children and young people in danger generates certain images of being in physical or emotional harm, this legislation extends the notion of harm beyond this more limited understanding. In this case, being in danger not only means being subjected to abuse and neglect, but also the absence of the conditions necessary to develop, inadequate education and training and infringements on personal dignity. As stated by the children's specialist, all of these issues can be encountered by children with disabilities. However, it is important to note that this legislation refers to children and young people in general and there is no particular mention of disability. Hence, the issues referred to above are viewed in the context of a child or young person without a disability. However, there is a difference between the needs of the two groups. For example, risks in education may refer to lack of attendance at school. For a child and young person with disabilities this means that

the school has to be accessible and adapted to fit their needs. There is a risk that children with disabilities are being judged by the standards of children in general, which can overlook their specific needs and whether their status is seen as being 'in danger'. Lansdown's (2001) criticises the coverage of children with disabilities in the UNCRC, arguing that the particular circumstances in which children with disabilities find themselves, and the particular challenges they face, needed to be emphasised in all principle articles of the convention in order to ensure their rights were guaranteed. Similarly, the legislation on protection of children and young people should highlight, in the article quoted above, that these issues apply also to children with disabilities and their particular needs. When the receptionist in the CNPCJR stated that her organisation did not deal with disability, it is because she saw children and children with disabilities as two separate categories.

6.4 Conclusion

This chapter sought to explore the legislative framework in which the interviewees worked. Various interviewees mentioned that the legislation regarding children with disabilities was up to date and met international standards and guidelines. As was illustrated above, that is to a certain extent true. On paper, at least, Portugal does meet all the international standards, with the exception of certain policies identified above which employ outdated or politically incorrect terminology. These policies will be discussed in further detail in Chapter 8. In terms of whether these guidelines and their goals are being fulfilled is where Portugal is falling short. There was much speculation within the interviews as to why this is the case. Some informants highlighted that there is a lack of funds to maintain a comprehensive structure to support the implementation of these policies, some identified the lack of coordination between departments as being responsible for this, while others talk about individuals not knowing how to access their rights. The informant for IR suggested the need for a specialised coordination body to tackle these issues. In addition, as was discussed in Chapter 4, the international guidelines themselves do not really suggest concrete measures with which to tackle certain issues. This lack of guidance is especially clear in the case of inclusion and social/environmental barriers. Perhaps

these issues have not yet been fully grasped or understood by policy decision-makers and, as a result, the concrete measures required are yet to be developed.

In terms of the provisions highlighted in this chapter, there was little mention of technical aids, which it could be argued are central to the normalisation process. As stated by the informant for SNRIPD, the area of technical aids is both no one's and everyone's responsibility. The ambiguity surrounding who is responsible for this area which has led to much inertia in responding needs to be addressed. There was, however, a heavy emphasis on the services surrounding children with disabilities. In fact, the majority of provisions highlighted were orientated at those providing for and supporting children with disabilities, rather than the children with disabilities themselves. There seemed to be an immense amount of pressure on schools to cater for the children who have additional needs, with what seems limited support from the state. Not once were the needs or best interests of the children with disabilities mentioned in the reviewed legislation and in the interviews.

As suggested by Allan (2006) the success of measures aimed at inclusion can be limited, if direct social networks are not taken into account. Children with disabilities were only directly identified in terms of cash benefits, and their benefits seemed to be linked to their status within education. These benefits are generally either orientated at the parents, service providers. This means that, according to policy, almost all provisions are allocated via the family or the carers of children with disabilities and are only aimed directly at the child themselves if they are deemed to be at risk. Hence, using Sim *et al.*'s (1998) construction of disability, according to Portuguese legislation all policy transactions take place at a micro, micro-familial or even familial level, but rarely at an individual level.

The education sector seemed to have a more comprehensive legislative plan regarding children with disabilities, and the interviewees within education seemed to have a greater understanding of their role within that context. Social security, however, seemed to highlight children with disability when regarding cash benefits, ECI and/or being at risk. Hence these civil servants tended to work with general

policy areas, e.g. children at risk or social protection, and would look at children with disabilities through that lens, rather than having a global view of children with disabilities. Although this approach has certain advantages, and could foster a more inclusive approach to policy, it may also lead to certain limitations as crucial areas may be overlooked. The following chapter shall explore these limitations in further detail by focussing on the professional identity of each interviewee.

7. Professional Identity and Policy Decision-making

7.1 Introduction

This study initially presented a basic structure depicting the decision-making element of policy-making. This structure incorporates various aspects that may influence a decision, and is based on the literature on decision making in the works of Fulcher (1989), Lipsky (1980) and Drake (1999). Each department within the public administration has different priorities, agendas and protocols on the different issues dealt with in that unit. A unit is made up of various individuals with different job descriptions, responsibilities and duties. Each of these entities has their own knowledge and understanding of the issues surrounding their job and/or unit. The duties and responsibilities of each unit can be influenced by both internal and external inputs and requirements. Furthermore, these can be dependent on the resources available, for example, the availability human, material or financial resources to execute a given policy. A combination of these factors will lead to a specific decision being taken, and will influence the process by which one executes a certain task or does their job more generally.

This decision-making structure was the basis of the interviews and data collection undertaken in the context of this study. The intent was to view the human influence on the policy chain, and hence the policy process. There were various themes that emerged from the data gathered, and various ways in which one could interpret that data. This chapter highlights the core themes which emerged, and the role played in this policy chain by the informants selected, each of whom is a key decision-maker in their particular field. Above all, this chapter will focus on their identity at work and the influence this identity exerts on their professional conduct.

To recapitulate, Drake (1999) stated that:

Civil servants and other officials may take an approach related more to professional identity than to political expediency. (Drake, 1999: 23)

Drake (1999) outlines a certain controversy as to the level of influence that bureaucracy has on policy making and implementation. He pinpointed three main reasons for this. Firstly, policies arise from different departments at different times and, due to this, they may be contradictory in nature. This intricate policy web can make it hard to comply with all policies or to develop a straightforward policy process that has equal outcomes at all levels at all times. Secondly, inconsistent policy guidance from the central government can lead to operational decisions being made at local level, which may result in variations in the application of certain policies. Drake's ideas have transpired in the data collected in the interviews. One of the most striking themes that arose from this data was the personal work ethics, professional conduct and identity that arose from each entity.

As highlighted in the introduction, this thesis sought to explore this phenomenon by using two of theories of identity to analyse the data. As discussed, identity is a complex issue, which is the subject of much debate. It can have contradictory definitions. On one hand, it can refer to 'sameness' where one feels one belongs to or 'identifies' with a particular concept, ideology, group or persona (Jenkins, 1996). On the other hand, it can refer to difference, where one possesses a unique identity. Since both SIT and IT are the result of an interplay of these ideas of difference (or uniqueness) and sameness, they were combined into one comprehensive theoretical framework to analyse the interviewee data. This chapter is divided into the processes that define each these theories; self categorisation (SIT) and role identification (IT). Firstly it shall explore how the interviewees categorise themselves, and secondly, it will explore what roles each of the interviewees adopt in their work. In addition, this chapter will look at how each interviewee identifies with other individuals and entities in the civil service and how they view their interaction in formulating policy.

7.2 Self-Categorisation in a Professional Context

Hogg *et al.* (1995) were adamant in distinguishing SIT from IT and have applied it to various contexts, including organisational contexts (Hogg and Terry, 2000). Hogg and Terry (2000) have used Tajfel's (1972) study of the value and significance of belonging to a group and the importance of finding one's place in society in order to

illustrate the basis of self-categorisation theory. Using this understanding of self-categorisation, they constructed an understanding of intra-group dynamics that could be applied to any organisational setting. They suggest that ‘identity-related constructs and processes have the potential to inform our understanding of organisational behaviour’ (Hogg and Terry, 2000: 135). This potential lies in the process of depersonalisation. Through the process of self-conception and self-categorisation, one is associating oneself with a prototypical identity. Furthermore, this prototype compiles a set of predetermined attitudes and beliefs. From an intra-group perspective, by belonging and identifying with a group, one also shares the same or similar beliefs and attitudes. These attitudes and beliefs are constitutive of the group and, hence, the identity prototype.

This section aims to apply self-categorisation to the interview data collected here and to view the similarities and differences in identity prototypes adopted by each informant. As part of the interviews, informants were asked to define what their job was and what they did at work. This section explores the self-categorisations which emerged from the responses of each informant to these questions, which shall be used in order to construct their individual identity profiles.

7.2.1 Introduction to the Professional Self

When asking the informants to describe their job, this question activated various types of schema which refer to the above theories. The first type of schema was an in-group self-categorisation schema illustrated in SIT. Three informants adopted this process as an introductory method to their answer. They categorised their job in a few words, taking an in-group perspective to their work place.

I am the Director of Services for the Directorate of Social Research and International Relation Services. (Informant for International Relations - IR)

My formal post is Director of Services of the Directorate of Special Needs Education for Special Education. (Informant for Special Needs Education - SNE)

I personally am the substitute spokesperson of the Directorate. (Informant for Portuguese Association for the Disabled - APD)

These categorisations were then followed by descriptions of that job and its position within their organization, as well as their role identification. These informants provided very concise and straightforward answers suggesting a straightforward understanding of what their job was. From an in-group perspective, the informants for IR and SNE also have ties with international organizations, but made a clear distinction between their job within the public administration and their roles within those institutions.

The informant for the Association of People with Disabilities (APD), however, being from a NGO, emphasised his detachment from the state and what his institution stood for, and was very clear about this. APD is an awareness-raising organization, which focuses on providing information on disability, fighting and lobbying for a more inclusive society. This informant highlighted his main responsibility was the independent-living movement within the NGO, which pushes for the equality of status of the disabled person when compared to the non-disabled person. He was very passionate in his portrayal of his organization, and it was clear he felt like a part of this organisation. This response is very different from that of the informant from the other 'voluntary' organization that has a partnership with the state. Similarly, there were other informants that categorised their identity as separate from their current job, meaning they had a stronger professional identification with roles they had performed or positions they had perhaps held in the past.

I work in public service. I am a teacher in a normal school, a regular school, and I am here for many years working on that area. My job is I am a public servant. I am on loan to the FENACERCI you see. I have been for many years working for FENACERCI, in a CERCI in one of the cooperatives. (Informant for FENACERCI)

FENACERCI stands for the National Federation of Cooperatives of Institutes of Social Security, (or the National Federation of CERCIS). These cooperatives are orientated at supporting disabled persons and their families, and although private, these cooperatives have support from the State. Whilst FENACERCI is the main global coordinating body of the 'CERCI' cooperatives, these CERCIs provides educational, vocational and occupational support for persons with disabilities. This

informant was not as straight forward as other informants about his professional identity at FENACERCI. He starts off by defining himself as a teacher, i.e. a public servant, and stating that he is on secondment. He seemed to feel he is not fully part of this organization, since he identified himself as being ‘borrowed’ by this institution. His main professional identity is that of a teacher, and although this is an educational establishment, he has only a managerial role within it. When asked what his main duties were as a worker for this organization, he was very clear, stating that:

I am a Director, I am more of a director than a worker (servant). I, in the case of these 2 organisations [CERCI and FENACERCI], I in the case of FENACERCI am the Vice-President of the Federation. I function as the Executive Director. ... Here in the CERCI I am also a kind of Manager of the Cooperative I am a specialised teacher. (Informant for FENACERCI)

The informant has a senior role in both the FENACERCI and at an individual CERCI co-operative. However, he still identifies himself primarily as a teacher, and his main identity within this organization is that of being a teacher. According to Stets and Burke (2000), identities need to be activated through being given salience at a particular moment in time. Working within the framework of SIT, Stets and Burke draw upon Turner’s theory of self-categorisation to highlight a three level hierarchy of inclusiveness in which different types of identities will be activated. These are the:

1. Subordinate level (e.g. Southerner)
 2. Intermediate level (e.g. American)
 3. Superordinate level (e.g. Human)
- (Stets and Burke, 2000: 231)

Salience and activation are dependent on the situation one finds oneself in, and changes according to the environmental stimuli. In short, this process of activation/salience is based on how accessible or appropriate an identity is perceived to be within a given context. This theory is very similar to that of schemas and schema activation, which argues that a particular stimulus activates a given schema, and that in turn initiates a particular cognitive process resulting in a specific response or action. In the case of the FENACERCI informant, his identity at a subordinate level was activated. He is a teacher and this identity is stronger than those associated

with either his current job in FENACERCI or the post he holds within his own organization. Carroll (1993) drew upon various elements of his previous 'lab' based studies, to elucidate an understanding of decision-making in organizations. In his work with Payne (1977), Carroll noted a schematic difference in responses between the two groups of participants; experts and students, who undertook his experiments on decision making in parole cases. They found that, while experts had real experiences on parole related matters and, therefore, more detailed schemas, students only had the general information presented to them within the study and no preset mental framework in this area. Perhaps because the informant for FENACERCI has exercised his career as a teacher for longer, he has a stronger identification with this profession. The informant for the National Secretariat for the Rehabilitation and Integration of Persons with Disabilities (SNRIPD) gave a similar response. Although she identified her current workplace and her associated job, she then proceeded to elaborate on her employment background.

I have only been here in the SNRIPD for 3 years, and have worked for let's say 20 and many years in the social security sector but half way I started working a lot in terms of direct intervention in a research centre for supporting the child and their family. Therefore, disabled children and not only... Children at risk... And as a result, in respect to working in direct intervention, whether it is with families whether it is with children whether it is with other professionals, and to a certain extent research and training, well we do a lot of training for other professionals. Well, I came here to the SNRIPD. I already knew and had heard of the SNRIPD. And obviously, more concretely, the type of attributions that the SNRIPD has, the attitudes that SNRIPD has developed throughout its existence since 1975. So, I came here 3 years ago and I think I knew to what I was coming to. (Informant for SNRIPD)

It seems this informant, a specialist in children's rehabilitation and integration, recognizes her department, the SNRIPD, as being her current workplace. However, she feels the need to elaborate that it is a relatively new job, especially compared to the twenty years or more she worked in the social security sector. Although this interviewee had worked in social security, she seemed to identify more with the policy areas within education rather than social security. This informant spent some time identifying her previous employment, before identifying her current workplace as an in-group, suggesting that she does not have a strong identity associated with her present job or the organisation in which she is working. As illustrated by the informant from SNRIPD, her perception of her work place is still influenced by her previous work experience. Furthermore, although this informant was always aware

of and interested in this department within the public administration, she had always seen it from an outsider's perspective. Within this informant's discussion of her current job description, one can see her internal struggle in making the transition from out-group to in-group status. Although this informant's introduction to her role seems similar to that of the informant for FENACERCI, her identity is still in a state of flux and not as firmly set as that of the informant of FENACERCI. There seems to be a will or intention to make SNRIPD an in-group, indicating once more that her schematic model regarding this post is still being formed.

According to Fulcher (1989), variations in policy can be accounted for by the different decision-making arenas involved in the policy process. These arenas all have different priorities or agendas, and the consensus about this may vary greatly. Whilst Fulcher focussed on policy-making in the field of special needs education, she made a distinction between the differing priorities of key political actors in the decision-making process. Whereas teachers may push for having smaller and more manageable class numbers with fewer children with additional needs, school heads may want to take in more children with disabilities, as this attracts more funding. Each of these measures are according to their own conceptions of their professional role and expediency, in the best interest of those advocating them. Hence, they are associated with their professional identity. However, as illustrated by the examples above, professional identity is not necessarily synonymous with one's job or what is required of one professionally.

Another type of identification that emerged from the interviews, was viewing the self as the collective. This form of identification was usually found amongst those lower down the hierarchy and in non-managerial posts;

We are part of one of the central services for the Institute of Social Security, as a result, we do not deal directly with the population. If it can be said we are in a sort of intermediate service that essentially accompanies the activities of the decentralized services of Social Security. (Specialist for Disability)

The informants of Institute for Social Security (ISS) were interviewed together. The Specialist for Disability quoted above tended to dominate the interview and tended to

talk substantially more than the Children's Specialist. However, the Children's Specialist did seem to agree with what the Specialist for Disability, and only intervened when she saw fit, or to highlight issues that hadn't been covered. She also seemed to be more settled in her identity and beliefs, as she was more clear cut and straight to the point than the Specialist for Disability. This may be because she had been working in that department longer than the Specialist for Disability. However, from the quote above, it is clear that these informants view themselves as part of a team, and not so much as individual practitioners. They also differentiate themselves individually from the both the top ranking public administrators and street level bureaucrats, taking a hierarchical approach to their post and the level of authority they are able to exert. It is only later on in the interview that each informant differentiates themselves as being specialized on disability and children's matters respectively. This collective identification also happened in the interview with the informant for the Regional Directorate of Education for Lisbon (DREL), but from a slightly more withdrawn perspective:

I am placed, at this moment, I am assigned at this time in the department for educational support, that belongs to here. The Directive of Pedagogic Services. This is therefore, in terms of the organogram, this is the Regional Directorate [Lisbon] that has Directives of Services. The Directive of Pedagogic Services in turn has many departments. I am in the Department for Educational Supports. That in a certain way supervises, organizes and accompanies these situations of Special Education Needs. Hence, of the students who have Special Education Needs. (Informant for the DREL)

This informant seems to identify herself being *placed* in her workplace (the DREL), and that this is not necessarily her own preference. Indeed, this informant had illustrated in the vignette exercise that she is a teacher by profession. However, unlike the informant of FENACERCI, she does not see this job as her profession. She is not a civil servant, she is a teacher. Similar to the informants from the ISS discussed above, this informant also needed to situate herself structurally in order to highlight her current role. Furthermore, she identifies her job through a collective in-group categorization. She views herself as part of the Department of Educational Supports. Both the informants from the ISS and the informant of DREL, positioned themselves structurally before outlining in general terms what their department does. As highlighted above, it is only after this description that the informants differentiate

themselves as individuals having an individual identity. As shall be discussed in the following section, this is usually done through role identification.

The final process of identification highlighted within the interviews was role identification:

I have been saying, the fact is that the type of responses that we have are in accordance with our regime of recognizing the rights and provision entitled to disabled persons. With what I am framed in, undergoing my functions in this organization, because it is this that requires that I, here, while an employee of the Directorate General and execute the politics of the Government in the matter of concrete cases, we are talking about the matter of protection for Disabled citizens, in this specific framework. And, what are my goals, which are my, in professional terms, what is my framing is the Social Security law-in-principle, the Programme of the Government and the Great Options of the Plan. (Informant for Regimes)

This informant is the Director of Regimes for what was then the Directorate General for Social Security Family and the Child, (now shortened to Directorate General of Social Security – DGSS). However, she only briefly touched upon this title. The informant opted for a more role based approach in defining herself. The informant depicts herself as working within a structure and fitting into a framework. As a result, she adopts a role and thus an identity within this structural setting. Referring back to the informants from the DREL and the ISS and (to a certain extent) the other informants, they too positioned themselves in a structural setting before proceeding to identify themselves with this setting. In fact, all the responses gathered produced a role-identification when describing one's job. It is hard to describe one's job without defining what one's role is or what one does. It is hard, in general, to define oneself without brushing upon certain roles or actions one undertakes. This is due to the fact that any identity we may have or take on indirectly implies a certain course of action. Nonetheless, the informant above seems to identify more with guidelines rather than categories or titles as such.

This thesis argues that identity is not just about self-categorisation, but also role identification. Although in terms of self-categorisation there was a distinction between the identities of certain individuals, perhaps in term of role-identification

one can find common traits and values between the informants. The following section shall explore identity in terms of role identification.

7.3 Role Identification in the Professional Setting

Hogg *et al.* (1995: 259) delineated the four main characteristics of IT. Firstly, IT takes a social psychological perspective on the self seeing the latter as being defined by social factors. In other words, individuals have socially constructed personas. Secondly, this social construction revolves around the occupation of structural roles in the social world. By associating with and fitting in to different roles, we construct who we are. Thirdly, as elaborated above, IT is based on role identification. Consequently, roles may vary based on their attributed importance. Through this process of identification, one selects the role that seems the most appropriate at any given time. Consequently, one transmits a sense of self through the roles one chooses.

As a result, IT mainly focuses on the processes of identification and the outcomes of the relationship between the self and society. Our social being, or rather the way in which we view ourselves, is defined by the existing social structures and how we see ourselves fitting into and/or accommodating ourselves within them. IT does not concern itself with the socio-cognitive struggle to find one's identity, but rather how we select, give preference to and adapt our identity to a pre-existing set of roles or identities presented to us. Hence, it is more concerned with role identification, and what roles and identities we align ourselves with.

7.3.1 Introduction to the Professional Roles

The concept of identity salience within IT places great emphasis on hierarchy. Stryker and Burke (2000) refer to the hierarchy of identities when confronted with particular situations and/or stimuli. They suggest that the more committed a role is to a particular identity, the more salient that identity is, where commitment is measured against the perceived personal and social costs of not fulfilling a certain role. Callero (1985), in his study of role identity salience in blood donors, divided role-identity salience into three categories: self-definition, social relations with the

‘other’ and behavioural consequences. Self-definitions illustrate not only how one defines oneself, and hence what one’s perceived roles are, but also the hierarchical structure that roles and self-definitions have. Furthermore, it also reflects notions of self-esteem, where positive self-esteem usually leads to salient role identification. Similar to SIT, role-identity salience is linked to one’s surroundings and one’s relationship with others. More salient identities have a clearer distinction of who the ‘other’ is, and are more likely to develop strong relationships based on this role-identity.

As Callero states: ‘role identities, by definition, imply action,’ (Callero, 1985: 205). However, the dynamics of the link between role-identity and specific behaviours is still debatable. Thus, although role identities imply action, they do not necessarily entail having a set given action. This was a shortcoming noted in Callero’s study. As previously discussed, salience can be affected by the situation and circumstance, and other surrounding influencing factors. In exploring this role-behaviour relationship, it is important to note that it is the resulting behaviour that is usually viewed by others and is hence validated.

Referring back to the FENACERCI informant’s perception of himself as a teacher, this identification could indicate the role he views as being imperative to his job. Although he is the Vice-President and Executive Director of his institution, the role he identifies with in this post is that of being a teacher. Since this is an organisation that primarily provides educational support, this informant refers to his experience of being a teacher as a basis for decision and policy-making in this area. Furthermore, given the nature of this institution, it primarily involves three groups: the organization and its workers, the state and its clientele. The informant only identified with two of those groups: the organization and the state (public service), but did not identify with the clientele which consists of persons with disabilities and their families.

In contrast, the informant for the APD identified his role within the independent living movement. What hasn’t been made clear until now is that this informant is

himself disabled, and although his disability was not directly discussed within the interview, this role identification was directly linked to his disability. This NGO has a different role to that of FENACERCI. It is not associated with the state, as was clearly identified by the informant. In fact, the state is viewed as an 'other'. This stance is particular to this informant, and is not as clear with other informants.

As previously discussed, top-level civil servants tended to identify with set guidelines within governmental policy plans. As suggested by the informant below, with guidelines are one of the main influences on their job and/or professional role:

I am in the section of Social Action. My job has technical/normative nature. I elaborate diplomas. These diplomas are a result of research and evaluations from institutions relevant to the issues at hand. I also define the financial co-operation and support to structures and institutions within each area. I collaborate in the conception of policies and elaborate their responses, within the framework of the Programme of the Government, towards contributing to the Great Options of the Plan. Before producing the Great Options, the Government asks for contributions and elects strategic scopes. After they elaborate the legislation, whether it be to improve the existing legislation or to create new options or responses. (Informant for Social Action [SA])

As highlighted in the Chapter 5, the Governmental Programme (PG) is the Portuguese equivalent of a party manifesto. It delineates the political strategy and guidelines proposed by the governing party(ies) for the duration of their term of office. Once in power, the government presents each year the Great Options of the Plan (GOP), which are the main policies to be pursued during that period. These highlight the policy plans and legislation for that year and are generally subject to the approval of the Parliament. These policy guidelines were referred to independently by the informants for SA and Regimes as an integral part of their job. However, it is important to note that not all respondents mentioned the PG or GOP, as did these two informants. This could be due to the other informants identifying more with other elements associated with their job, or that they are taking the interviewer's knowledge of these aspects of the policy process for granted. However, there may be other factors associated with this lack of emphasis:

So, here there has been some frustration, because then things get done, but then at Governmental level and tutelage of various Ministries is when things get complicated. The things go, stay months, years in the drawers. The Government changes, the organic structure

of the Government changes. For example, in a space of 3 years that I am here, the issues associated with the Government changing 3 times aren't resolved. So, in the previous Governments, hence Durao Barroso and Santana Lopes we passed from a Secretary of State, after 2-3 months we were linked to Ministry of Social Security then we passed to the tutelage of another Ministry for 2-3 months, then another Secretary of State to do with Social Security, then to do with Employment. Then the Government changes to Santana Lopes. Even within the same party we were placed in the Presidency of the Council of Ministers. This Government only was in power for 6 months and we were linked to 2 different Ministries. We had one then 2 months later we had another.... (Informant for the SNRIPD)

As highlighted above the informant for the SNRIPD had been in that post for three years at the time of the interview. In that time there were three changes of government and numerous structural changes within the secretariat. As a result, one can understand the uncertainties or erratic schemas this respondent has regarding her work and role. Furthermore, there is a lack of emphasis on the government evident in her responses. The SNRIPD is a specialist organisation within the public administration. According to the Regulatory-Decree 56/97 of the 31st of December 1997, the National Secretariat for Rehabilitation and Integration of Disabled Persons has the 'aim of planning, coordinating, developing and executing National policies for prevention, habilitation, rehabilitation and participation of Persons with Disabilities' (Regulatory-Decree 56/97). Although in terms of legislation these parameters have remained constant in the last three years, due to the changes in government highlighted above there have been major transitions in the organisational structures responsible for their delivery. As a result there have been backlogs and limitations to the influences and changes this small entity has been able to make. Furthermore, individuals working within this context may feel insecure about their professional *raison d'etre*: where they belong and what they are supposed to do.

According to Decree-Law n. 211/2006 of the 27th of October 2006, the DGSS also started working alongside the Ministry of Employment and Social Security. This is a result of a transition of Government from Pedro Santana Lopes (Social Democratic Party) to Jose Socrates (Socialist Party). The ministries above were restructured and the Ministry of Social Security, the Family and the Child ceased to exist. Consequently, as was highlighted above, the DGSSFC was restructured and renamed the DGSS. Previously, under the Social Democratic government of Jose Manuel Durao Barroso that preceded the Santana Lopes administration, the D-G in question

was also known as the Directorate-General for Social Security and came under the auspices of the Ministry of Employment and Social Security. Despite the fact that both the Durao Barroso and Santana Lopes administrations were drawn from the Social Democratic Party, the structure of the ministries in question were under Durao Barroso's government was more similar to that of the current Socialist Government than under Santana Lopes.

Similarly, the equivalent D-G for Education has changed too. Initially, under Durao Barroso, the Directorate-General within Education was entitled the Directorate-General for Education Administration. Under Santana Lopes, the Regional Directorates for Education and the DGIDC came in to being, and this structure remains to date. For large entities within the public administration, these changes, whilst still strenuous, are less so than for smaller entities such as the SNRIPD. It is also worth noting that SNRIPD is a relatively young body. It was established in 1975, which coincides with the end of the dictatorship.

In looking at the GOP and PG, the DGSS is has the function of:

Being integrated in the direct administration of the State, whose mission is of conception, coordination and support in the areas and regimes of Social Security. This includes protection against professional risks and social action, as well as, the technical negotiation and coordination of applications for international instruments relative to legislation of social security and social action. (Decree-Law n. 211/2006:14, 27/10/06)

The role of the DGSS includes reinforcing the effectiveness of social security, proposing norms and regimes within this area to tackle poverty and promote social inclusion, advocacy and mediation between national and international policy, applying international instruments regarding social policy and researching professional risks that may cause an inability to work. As highlighted above, these objectives can regularly be subject to change. From a Social Action and a Regimes perspective, both the respondents for SA and Regimes highlighted their main functions as being of a technical/normative nature, supporting the guidelines set out by current legislation.

In contrast to the informants for SA and Regimes, the Informant for International Relations (IR) for the DGSS, has described herself as a mediator between international and national policy. Hence, as discussed in chapter 4, she looks to international policy structures and guidelines to aid her work:

I am linked more to the international part and that is my line of work and I have been in this field for a long time. What the Directorate General does and what the services are provided by Benefits and Social Action is linked to International Relations, UN, European Council, European Union, the social security related Associations, the international Association for Social Security, the European Federation for the elderly, and here are some of the International Associations for Social Security. (Informant for IR)

As was touched upon above, the Director of SNE also collaborates with the European Agency for Development and Special Needs Education (European Agency), and notes the importance of keeping up with international developments, as did the SA participant. Similarly, various interviewees mentioned the use of international guidelines. However, the majority of informants couldn't speak English or any language other than Portuguese and, therefore, could not access international documents, unless they were translated into their mother tongue. Thus, there was a reliance on the IR sections to filter through the necessary information, and that is how the others conceived her role to be. It is important to note, however, that this informant's perceived role correlates with the legislation set out above regarding the DGSS's mission statement.

Within education the respondents had similar approaches to that of the respondents in social security:

This is a department that works at a national level, and therefore, the competencies of this department are directed at supporting the policy requirements, regarding the preparation and organisation of legislation, creating and publishing orientating norms and monitoring the guidance of the system's regulation. It is basically comes down to having roles such as conception, normalisation and guidance and implementation. (Informant for SNE)

The informant for SNE started by defining herself as the Director of Special Needs Education, she located herself structurally within her department and its guidelines. Similar to the DGSS, the DGIDC also has a technical-normative element to it according to Decree-Law 213/2006 of the 27th of October. This unit looks to

formulate and implement policies regarding education, via processes such as conception, research, orientation and guidance. The informant at hand directs the department which specialises in special education and special needs. Furthermore, although she has outlined her role in terms of the general function of this unit, as well as specific material provisions it provides (such as having a braille printing service), she did not touch upon her role in the special needs process. While she did highlight certain factors regarding this, her identification with her work was directed more towards the policy process than content, a distinct approach when compared to other informants who are also specialists within the disability field. In general, the more senior civil servants seemed to be more prone to taking a top-down approach regarding policy decisions and their work-role identification. Perhaps this may justify the SNE respondent's detached approach to disability when regarding her work role-identification.

Thompson (1979) has explored compassion within organisations. His book, *Without Sympathy or Enthusiasm*, explores the lack of compassion of public servants and/or workers within large organisations. He states that these organisations are made up of 'specialists who deal not with human beings but with categories of problems' (Thompson, 1979: 8), and who are 'psychologically incapable of becoming personally and deeply involved with all these people' (Thompson, 1979: 9). With experience, the novelty of a particular phenomenon wears off. As a result one becomes numb to certain stimuli or circumstances. In reviewing the interview data, it is clear that certain respondents demonstrated more emotion than others. Most informants within Directorate-Generals tended to give very short, concise responses regarding their role at work. One reason for this could be that they have limited, set identities regarding their role at work, or that they were more set in what their work was because of their extensive experience in performing that role. However, in addition to this analogy there may be a problem of administrative disenchantment, where someone loses their compassion for the policy beneficiary.

The extract from the interview with the informant from the SNRIPD cited below portrays an enthusiast, someone relatively new in her job, who has worked directly

with people in the field, and would now like to contribute to building a bridge between policy and implementation.

In another work level, not so much linked to direct intervention with the people, but it makes me to know I have first hand experience. It also helps and furthermore I always had a particular taste for research, investigation and therefore it was an opportunity and to also give my contribution. Relatively speaking to make a bridge between direct action and also a particular support in conceptual terms, as well as being able to take action in relation to the type of work that is require here, which also has to do with developing specific studies. Or, evaluate specific implementations and interventions in the domain of disability. To make proposals at policy-level which relate to issues regarding the area of disability. This was what I was expecting to do and this is what I am doing. (Informant for the SNRIPD)

This enthusiasm could be due to her still having an element of compassion due to her direct work with disabled persons within small organisations. This compassion has transpired through to her current work as she has work with people and categories of problems which still reflect real people as opposed to just categories of problems. Furthermore, that there is a strong bottom-up approach to her work-role identification. Thus, she is taking into consideration the needs at a street-level rather than at the governmental level. Furthermore, the SNRIPD is a specialist secretariat on disability, indicating that any professional identity generated from this work place is linked to the area of disability. This contrasts with the informants from the DGSS, who had more general social security roles rather than being disability specialists.

Working within the field of special educational needs in the DREL highlights that the concepts of 'disability' and 'special educational needs' play an integral role in her work-role identification.

This unit, in a way, supervises, organises and follows through these situations of Special Education Needs. Hence, of the students that have Special Education Needs, let's say that here, when they are students with Special Education Needs, it already expands the issue of emotion, because the problematic of emotional factors, the problematic of language, of communication, we cannot consider as a disability. The Special Education Need already is a different concept. We all have special educational needs.

But in any way disability, the concept of it is chronic to Special Education Needs at the moment. Let's say that the support that we could give a child is for her to overcome and resolve. Hence, at the end that and thus work that is done in this office is a work that is done at the level of guiding institutions, not only guidance but also catering for the resources at a staff level of the beneficiary, at the level of the official schools, the private schools. Let's say there is a guidance for everything that the Students with Special Education Needs, that are in the Special Education System that is done there by us. (Informant for the DREL)

Whereas Chapter 8 shall deconstruct the conceptualisation of disability and related terminology, it is important to note the contrast between this respondent and the informant for SNE in the DGIDC. Both work in the field of Education. However, the DREL respondent is not a Director and hence does not have a managerial role. Instead, she supports and guides street-level institutions, and deals with real cases. Although this informant and others at a similar level do have to follow certain policies and protocols, their main policy stimuli comes from the street-level rather than at governmental level. In fact, the informants for the ISS, especially the children's specialist, emphasised that although she follows current policy her main concern is meeting the needs encountered at street level.

Other civil servants highlighted their departmental activity plans and/or existing legislation. In the case of SNRIPD, this interviewee highlighted her departmental plans, as well as the Government as a source of influence on the policies she undertakes.

SNRIPD has a plan that is developed yearly. And there is altogether an organisation of labour associated with that PA (Plan of Activities). It is distributed through the sectors. Concretely in my case, there determined work areas that affect me. So this is in terms of the internal organisation. However, in addition, this is intercepted a lot by requests and orientations that come from the Government. And when I say requests, or be it policy orientations that are defined calmly but we are always being intercepted from day to day this and that and the other and now you do that and now you do this so we are always being intercepted at that level. I think there it would be important to perfect this interaction between governmental departments and services. So here concretely and surely would bring disadvantages in terms of what is being done. (Informant for SNRIPD)

This interviewee seems to view the requests from the government as more of a distraction or interference with her job, than part of her job and her departmental plans were her main influence. It seems that the dividing line between top-down and bottom-up approaches intersects at the level of the SNRIPD. This structure could be highly effective, provided there is an effective mediator between the two. Within the disability field, it seems that the SNRIPD would be highly successful. However, the fact that this unit is a unit in constant transition seems to be detrimental to its effectiveness.

Within Portugal, as a result of the lack of resources and social provisions, there is a heavy reliance on partnerships with the voluntary sector, and on the family to provide assistance to those with disabilities. Interviewing informants within the APD and FENACERCI has produced compelling results, in terms of their role identification regarding their organisations and, furthermore, in relation to the state.

What I do I do? I am responsible for all the operation of this Federation. I have one responsibility that is more political than technical. But, all kinds of work pass through me, work in training, work in research-action, work regarding the proposal of auto-representation of disabled persons, links to the family, public relations, international relations, etc. This in the area of FENACERCI. Here in CERCI I am also a type of manager of this cooperative, I am a specialised teacher. But basically what I do here is manage human resources of people who work with people with disabilities. So at this moment that is what I do. Aside from providing training in these areas of ethics regarding technologies of auto-representation and so forth. (Informant for FENACERCI)

The idea of institutions funded by the state is a contentious issue. Given that each of these institutions have their own unique agreement with the state, it is hard to include all these organisations catering for different areas and issues in one homogenous group or definition. Similarly, depending on the nature of the institution, there can be a distinction between who they are more likely to work close with and have similar goals. The informant above works within FENACERCI, one of the largest and best known organisations. This interaction shall be explored further in the following section on ‘Identifying and Interacting with Other Professionals’.

The informant for FENACERCI speculated that the reason so many people with disabilities are integrated in the labour market is because of private-public partnerships.

There are thousands of people with mental disabilities who already entered the labour market, which 25 years ago was unthinkable. That evolution only was possible in fact, because there was work in a partnership between the State and the Organisations, which achieved these results. (Informant for FENACERCI)

The relationship between the State and the voluntary/private sector is hard to define in terms of the direction in which influence is exercised between the two. One could define it as a bottom-up process as these organisations lobby for specific public rights and needs to be met, and/or to raise awareness about these issues. However, it

could equally be seen as top-down process, as some of these organisations provide advice in formulating policies, and have to adapt to state policies in order to secure funding. Reiterating the quote above, if it was not for the partnership between the state and these organisations, change would not have happened, or at least not that fast. It is clear that the State relies on these partnerships to ease their burden in distributing of social welfare. However, the dynamics of this partnership between the state and the voluntary sector was only highlighted by respondents after significant prompting. This partnership will be discussed further in the following section.

In parallel to CERCIS that has an agreement and an institutional role in association with the State, where CERCIS takes upon a series of functions, that are paid for by the State. APD doesn't any type of agreement at that level. This is because the mission of APD is different from other Associations. (Informant for APD)

This informant views the NGO he works for as being independent from the state, and further distinguishes between his NGO and FENACERCI. This distinction is not only due to APD's detachment of the state but also the nature of the institution.

I also have shared responsibilities in the core of accessibility. APD is an organisation that defends human rights. It is also a NGO whose mission is to fight for the integration of people with disabilities, irrespective of their typology. Therefore it is a universalist organisation, hence, not only the type, the general main mission is to defend the rights of these people and for all levels of society. (Informant for APD)

Being a human rights/awareness-raising organisation, APD provides a consultancy and advocacy service rather than social action and provisions. This organisation looks to raise awareness and advocate the integration of disabled persons into society, indicating that, as things currently stand, disabled persons aren't fully integrated. Interestingly this institution seems more inclined to pushing for integration rather than inclusion, which for people with disabilities would presumably be the more attractive option. Perhaps this is due to the influence of international guidelines to be discussed in the following chapter.

This disenchantment with the state can lead to disassociation with it, and it being identified as an out-group. Their aim is to criticise the state and society and suggest changes that will benefit their members and cause. It is clear that this informant, who

himself has a disability, feels strongly about these issues and, therefore, entitled to raise awareness regarding issues involving disability. This is also a marked distinction between the two NGO respondents interviewed here. Whilst the interview discussed above has an insight into living as a person with disabilities through his own experiences, the other has experience of supporting people with disabilities. Consequently, each respondent is working in an organisation related to their own particular insights and perspectives. Unfortunately, as is reflected by the interviewee from FENACERCI, these issues are usually related to adults with a disability and not to children with a disability.

Departmental approaches weren't always identified within the interviews. In the case of the informant for Special Needs Education (SNE), although she may have had departmental agendas, she seemed to identify more with her interaction and dealings with other entities. Perhaps because she works closely with the government to develop policies and legislation, and also has a managerial role within the DGIDC, her job changes on a regular basis and is constantly developing. The informant for the DREL, on the other hand, does not have a managerial role and works more on the implementation side of policy, rather than on the conceptual side. She stated that although some things do change, there are certain aspects of her job that remain the same for long periods of time:

Each sector, each office, each department has an activity plan. And then we assume that the Directorate General will also have. But we there have our own Activity Plan, the office has an activity plan and all the offices have annual activity plans. So every year we need to do it. Although there are tasks that remain; creating the network for educational support, we did that, before, now that will change with the panel isn't it. So there are the speech therapists, the sign language interpreters... so we create. We create the network of teachers for the institutions, so this is a yearly situation. It is always part of the plan. With other tasks that are fixed. So there are fixed situations that have always been maintained, and there others we go along trying to changing. And that has to do with the current needs. This year we have a need to work closely with CERCIS and the other schools. Isn't it. There are so allocations to these places to follow, understand how things are done, support these institutions to change an improve their services to these children. Every year we try to develop this activity plans to meet the most recent needs. So in formulating our responsibilities, the requirements from above and the needs and priorities are all taken into account. So besides a better following of private institutions of special education we also are working closely with coordination teams of educational support, which was different from last year. (Informant for the DREL)

Although, the interviewees seemed reluctant to share their departmental activity plans, they did highlight what they identified as the most significant points. In the case of the informant of DREL, she highlighted that prior to the plan to create a Panel for Special Education part of her yearly activities was to create a network of educational support. In addition, she also creates a network of teachers that are available and can be placed in institutions where they are required. These are the tasks she has to do on an annual basis that do not really change from year to year. Now, with the creation of the Special Education Panel, things will perhaps change slightly in terms of what her role entails, but once this new measure has bedded in, her role will once again settle down. In addition to the fixed yearly tasks, new goals are produced in order to meet current and emerging needs. The informant for the DREL mentioned that the year's goals for 2005 was to support private institutions providing special education and to work with, evaluate and support the development of the coordination teams within this area. This is important as Portugal has been criticised by the OECD for the apparent lack of communication between the different tiers of government and the competencies of each are not clearly defined (OECD, 2003). By having this evaluation and support service, it allows the state to monitor its investments and provisions.

FENACERCI is a regional federation, that represents 51 cooperatives at national level, that works with children, young people and adults with disabilities. Particularly mental disabilities, but not only. So that federation doesn't necessarily provide a direct service to those children and young people, but it supports the organisations, those 51 organisations in their development, in terms of occupation, in terms of support. So it is those organisations that work directly with children, young people and adults, and their families, and I also work with one of those organisations. I work in CERCI Peniche. It exists in Peniche and works with children, young people and adults. There we have a special education school. We have a centre for children and young people until the age of 18. We have a vocational training centre specialised to that kind of people. We have an occupational support centre that is orientated at people above 18 years of age that do not have the conditions to enter the labour market and we invest in quality of life. And we have a residential unit, although it is small, it is for people with mental disabilities. And then we have other structures that are open to the community. Centres that recognise competencies, so for people with disabilities and without. We have an 'active life' unit that helps one find employment and is open to the public. So we are organisations that are a bit complex. So the federation coordinates or rather represents the activity of those 51 organisations, giving help in terms of internal organisation, training, represents together with the political power, and promotes initiatives of awareness-raising to the problematic of mental disabilities. (Informant for FENACERCI)

FENACERCI is the federation that coordinates the 51 CERCIS that exist nationwide. As noted throughout the interviews, this is one of the main organisations that offer

support to people with mental disabilities, regardless of age. This informant indicated that it is mainly people with mental disabilities who use their services, and that services are usually tailored to education, vocational training or employment. This could be because the main group of people who require educational support are those with learning difficulties. However, each CERCI has its own range of services that are tailored to the geographical area they reside in, and the perceived needs of those within that areas. Just as the goal of the DREL is to support institutions such as CERCIS, so FENACERCI too aims at supporting CERCIS in terms of their organisation, skill sets and political engagement. Many of the priority areas highlighted by the informant for FENACERCI were very similar to those of the government and the informant for SNE. Perhaps this was because that year FENACERCI was receiving guidance from the civil service and in particular DREL.

Look we have a contract with the State that we provide services in various domains and the state helps with the finance of that provision of services. We receive an amount of money for each person that is in the centre of occupational support. Then we distribute that money. We pay resources, buy materials, and so forth. You see. It is hard to explain generally because for each activity is different. Each entity has their resources, you see, then in terms of resources we have to think is it human resources, financial resources and physical resources, let's put it that way. Human resources are contracted in terms of the type of services that the organisation has and also the funding we can secure. Physical resources, and we are talking about installations and so forth are sometimes partially funded by the state, but are paid integrally as part of maintenance of each of the organisations. Each CERCI is responsible for their resources, even FENACERCI is not responsible for that. Flexibility is based on the funding we have. We can build whatever we want, for example, if we wanted we could do an apartment building with 50 floors, we could. The problem is having to money to do it, and then having the money to maintain it. Sometimes it's not the construction cost that is important, it is the maintenance cost. The great problem of these organisations is the sustainability. Because for us to construct we have to get it from the support, support from the state, from Europe, and so forth. But after maintaining the structure is probably very complicated because every additional time the financial entities are more and more restrictive. (Informant for FENACERCI)

According to the informant for FENACERCI who also runs CERCI Peniche (a town north of Lisbon), each CERCI is responsible for their structure, function and resource allocation, to the point that he stated that these issues are not the concern of FENACERCI, which is not able to influence these decisions. CERCI's have complete control over their budget and their function. The main driving force behind the decisions made regarding provisions and services is based on funding and whether proposed measures can be afforded and are sustainable. As a result, various measures are provided because they bring in funding rather than being an actual priority of the

institutional. Secondly, provisions are made according to need. However, if there is a high incidence of a certain disability, then the CERIC will adapt accordingly to meet those needs. The CERIC aims to provide services that are not being provided by others, and to use the local resources and structures to do so.

7.4 Identifying and Interacting with Other Professionals

Aside from written guidelines, the interviewees identified their relationship and interaction with their department and other entities as an influence to their job. Here we enter what Fulcher (1989) identified as the political arena, where interests conflict and must be compromised. The relationship between the different political actors and the actors in the school setting, such as teachers, head-teachers, local educational authorities and so forth, is less clear and the effects it has on decision-making are more ambiguous. This is because it requires us to explore aspects of human interaction and perceptions. This section explores the impact of human interaction. It looks especially at the conceptions and perceptions of what is expected of the self and others, and what others expectations are of both us and themselves. It is divided into three sections dealing in turn with departmental relationships, inter-departmental relationships and public-private partnership. These were the main public arenas that were identified within the interviews as having influence on decision-making.

7.4.1 Inter-departmental Relationships

In viewing policy as a process of decision-making, it is clear that each decision made at each level impacts on subsequent decision. Within the interviews, the informants from the civil service highlighted the importance of their relationship with other governmental departments in reaching policy objectives and outcomes. As highlighted above, during the course of the interviews it was announced that special education panels for schools would be set up. When asked how decisions were reached within her department, the informant for SNE highlighted the following example:

I'll give you a concrete example. You heard the Secretary of State announce in the ECI seminar that Special Education Panels will be created within Schools. Until now the teachers would be sent to schools for a year, the year would end and what we saw was that the instability was so great that we needed to address it. It was the policy of the Government to

advance to creating a Panel for Special Education. Or be it, in each grouping of schools, I don't know if you know, there is a type of grouping, a type of 'cluster schools' that covers schools from various levels, from pre-school to primary, secondary and tertiary. In each grouping, each grouping may have 800 students, 500... 1000... 1500... Thus, a Panel of Special Education was created. Consequently, in order to create a Panel for Special Education, what happened? The Secretary of State asked me to think of characteristics of that Panel. Special Education is a teaching group, at this moment it is a teaching group, as is English and French or Philosophy, thus it is a teaching group. He asked me to think about how to create places in that implementation. I made a proposal, that proposal was accepted and is in the legislation. (Informant for SNE)

At the end of the interview, informants were asked how decisions were reached in their organisation. The informant for SNE answered this question by highlighting the example cited above. The Secretary of State for Education asked her to formulate a proposal for the integration of Special Education Panels into schools. It was noted that the use of free-lance specialist teachers resulted in erratic outcomes and that a more integrated approach was therefore necessary. This informant formulated a plan that was accepted by the government and made into a piece of legislation. Once the legislation was in place, the informant was asked to think about how to implement this legislation. This implementation required her to consult Regional Directorates, and to formulate a plan for the implementation of the measures contained in the legislation. Although this relationship with other departments will be discussed in the relevant section below, it is important to note where in the policy process the influence of the government becomes clouded. This is the point where the civil service begins to direct policies and where the policies themselves take on their own personae or direction. This transition has been noted in the interviews. As may have been noted, other interviewees within the field of education were not mentioned by the informant for SNE. This is not coincidental. None of the departments below the D-Gs (aside from SNRIPD) who provided interviewees for the project mentioned the government and its influences. Even the informant SNRIPD highlighted the government as not being her main influence (although it was one) in her workplace. Legislation played a bigger role. However, the one time that the informant for the DREL indirectly mentioned governmental intervention was in reference to the Special Education Panels.

The next step is that now we will create those posts, isn't it. So, for us to create those places on the Panel, what did I do? I did a network with the Regional Directorates, it is a network that I have in systematically in place and I defined criteria with them, isn't it? So, we defined

criteria to create each place. For example, I'm going to tell you that in a general way for every 500 students in school, 500 students said 'normal' we put one teacher in place and we also placed more teachers every time there is a concentration of students with disabilities that is higher than usual. Isn't it. So, we studied, we worked with a incidence rate of relatively 2% in schools in that which regards children disability, which we think is a reasonable rate. We also defined other criteria. This criteria defines those posts. I created a factual basis for each Regional Directorate. Each Directorate has a password, and made a proposal to create the places using the criteria, they placed the data on the internet and now I am investigating it. So, it is based on that investigation that I will put it forward to the Secretary of State and those places will be created. This is the process by which this matter was undertaken. Other areas follow a similar process. (Informant for SNE)

Having defined the criteria for each post regarding these panels, this informant then established roughly how many posts should be available. In this case, for every 500 mainstream students - or, as they were termed by the interviewee above, 'normal' students - there will be one teacher. More teachers will be allocated if there is a higher incidence of disability in any particular area. Using the criteria and guidelines developed by the informant for SNE, the Regional Directorates such as the DREL had to research what posts were needed their regions and present their data to the department of the informant of SNE. The interviewee for SNE is then responsible for reviewing that data and forwarding the relevant information on to the Secretary of State to get their approval. This is a similar process to that employed in the Special Education measures highlighted above. The DGIDC produces a manual with all special education resources available to the country. Schools put in a bid for these resources based on an assessment of the particular needs of their pupils. These bids are then reviewed by the Regional Directorates, who report in turn to the DGIDC and, more importantly, to the informant for SNE. The informant for SNE then evaluates this process and produces a report stating what provisions are being made to schools, and what further support and provisions are needed for future reference. Hence, this is why the informant for SNE stated that other areas follow similar processes. She has an overall coordinating role of all special education measures within the civil service.

The informant for the DREL also mentioned the Panel for Special Education, and her department's relationship with the DGIDC:

In our activity plan we didn't have this panel of special education. Isn't it? So we have always to adapt and alter, there has to be a great flexibility in all this. So we have to

reorganise and there are some colleagues that have more vocation to do this work than others, so in terms of the group there has to be a reorganisation of work and the so-called flexibility to respond to what is asked from us.

Depending on the situations, for example, there is here a Director of services, that let's say has confidence in her group and delegates within the group responsibilities. So let's say she does that, but then we organise ourselves to do it. Of course, there is always a point or another that we have to respect isn't it. They have to do with policies that are imposed, isn't it. But after there is flexibility and let's say the group tries to achieve, taking into account the Director of services, what we are doing. And so the Director of services... there is always a spelling out of wants and wills, and there is freedom to the kind of things our office wants or thinks that is the best. Always in conjunction with the Director of Services.

When I was saying about this freedom, when I was talking what I meant was... look.. from going to schools, this pedagogical and psychological support. So there are situations where, there is freedom from our part and we apply our knowledge and experience of life. So we do that. There are others where there are specific guidelines. That we have to do in that way, and in that manner, and in a way that in this case of the panel I can give any further information but part of the Directorate General gave us specific guidelines of what needs to be done and this is being done. (Informant for the DREL)

The informant for the DREL highlighted her role as being one in which she enjoys a great deal of flexibility. This is a phenomenon that emerged constantly through the interviews, especially this one. With different tasks and responsibilities come different levels of flexibility in terms of decision-making power. As mentioned above, this interviewee has a certain flexibility regarding long-running provisions and initiatives. She stated that, when making decisions, she would apply her knowledge and life experiences. As a former teacher, the knowledge and experiences she has is not of receiving educational support, but of administering it. Therefore, the group she will identify with the most is teachers and those providing the support to young people, and, as was argued above, she structures her policy-making accordingly. In the case of the Special Education Panel, she has to adhere strictly to its associated guidelines. This is primarily because it is a relatively new measure that is in its early stages of implementation and is being monitored carefully by the DGIDC. However, the main influence is the Director of Services within the department in which the informants for the DREL is situated. It is through her that responsibilities are delegated and mediated.

And in this case the Directorate-General has a department linked to Special Education. Yes. We have monthly meetings. But now with the panel we communicate with them more

frequently with this department to facilitate. It's not only about what we do here, but also to try, in those meetings the other Regional Directorates go. So there are 5 and representatives from all go. So that at ground level there are guidelines and identical guidelines. What would happen a few years ago, was that the North would do something, some dates would come up, Alentejo would have others, here we would have others. So what would happen? Each one would manage each of their areas their own way. So lately there has been an effort to let's say manage the 'house', which isn't easy, more or less uniformly. So the specificities of each zone is respected but after there is the same competitions are dates. (Informant for DREL)

In terms of the relationship between this informant and the DGIDC, she stated that all regional directorates meet monthly with the Special Education Unit of the DGIDC. The informant for SNE too had mentioned her 'observatory' that reviewed the special education measures and evaluated their relative success. The informant for DREL stated that these meetings emerged after it had noted that the Regional Directorates differed greatly in their measures. This was due to the Regional Directorates having a considerable amount of devolved power and, as a result, educational support services were not uniform. However, the informant for the DREL had mentioned that she made decisions based on her own life experiences and that she had a certain amount of flexibility in making decisions on provisions. If this is the case for all civil servants in all Regional Directorates, then presumably each one would have different life experiences to refer to when making decisions. For a system to be uniform it cannot be flexible. However, uniformity is not desirable, as it does not allow for provisions to be pluralist and tailored to each situation. The informant for the DREL noted that some uniformity was necessary, at least in terms of making certain dates and public competitions concurrent. Similarly, the informant for SNE was also concerned about uniformity in terms of providing stability. The goal of the Special Education Panel was to have a more uniform and stable structure to special education.

According to a communiqué from the Ministry of Education (2006), specialist teachers would fall into three domains:

- E1 – Special Education 1 – Supports children and young people with severe cognitive problems, with severe motor problems, with severe personality or behavioural disorders, with multiple disabilities and for ECI in childhood.

- E2 – Special Education 2 – Supports children and young people with moderate, severe and profound hearing impairments with problems of communicating, language and speech.
- E3 - Special Education 3 – Educational support to children and young people with blindness or low vision.

This criteria suggests that children or young people who require support from specialist teachers fall into one of three categories: those with severe mental and/or physical ‘problems’ or disabilities; those with hearing impairments and finally those with visual impairments or blindness. There are a few issues that arise from these criteria. First and foremost, educational support was only mentioned with regard to visual impairments and although these provisions are associated with schooling, this concept should be reaffirmed in all disability groups. Secondly, the wording is slightly oppressive, especially in the E1 group which states that children with cognitive and physical impairments have ‘problems.’ By using this word, it suggests that there is something wrong with children with these disabilities which need to be fixed. Furthermore, there is no mention of children that have learning difficulties that are not very severe, but which still need support. The more one reads into policies and legislation, the more it becomes clear that the Portuguese language is quite limited when it comes to the vocabulary concerning disability, which in turn becomes limiting.

The informant for IR had stated that there was a need for some kind of umbrella organisation or ombudsman, to deal with information on certain areas at all levels:

We are a fundamentally an organ of implementation, of circulation of information, also to local services. At that level we are well positioned, to do reports and it is an important role of our work. And also the relationship between the D-G and the different organisations of Social Security, is also very important. Just as we learn from others, we also have something to contribute. (Informant for IR)

From the above quotation, it seems that she feels the current structure is lacking in this area. However, in describing her D-G she described it as an organ of implementation and circulation of information at all levels. This informant highlighted that they produce numerous reports and compile various information, all of which are accessible on the internet. However, this suggests a reliance on others to search for this information and to understand it in the way that is intended. Perhaps

she feels this information can be made more accessible. In addition, this informant feels that it is important to maintain a good relationship between departments. Knowledge transfer in this context was felt as being valuable, suggesting that this is currently not the case. Indeed, the informants within the DGSS mentioned their links to this particular department, especially regarding the international arena, but this was not the case for the other interviewees.

The informant for SA commented:

The DGSSFC supports local ISS (Institutes of Social Security), puts normative regulations in place and supports its function, through the agreements with Districts and Institutes within these Districts. The Protocol of Cooperation is signed by District Centres and their Institutions, and is celebrated annually. Unfortunately the evaluations of these protocols are insufficient. Portugal has an unsustainable number of Institutional discrimination. (Informant for SA)

The informant for SA also works with intermediary bodies (the ISS and district centres of social security) to address the needs of the public. However, as previously stated, there is no state provision for social action, but rather private-public partnerships. These partnerships are bound by protocols which are usually organised through district centres and the ISS. This is a similar process to that which takes place in the field of special education. However, as noted above by the informant of SA, it is hard to monitor the effectiveness of these protocols and whether the various entities involved in this process are abiding by their terms. This leads to a series of problems and limitations in the system and in the provisions required. According to the informant for SA, there are 'work groups' in certain areas that have the responsibility for evaluating services and provisions. She gave the example of ECI that is currently in action. These evaluations usually undertake an analysis of information and of data in this area and result in an alteration of legislation:

Social Security has monthly sponsoring for that response. So this evaluation is made as soon as I seal an agreement for cooperation. It doesn't imply that I also do the evaluation. That will be done, in a form of pedagogical support, by District Centres to the Institutions. If they want to change some of the provisions, would like to tweak certain situations, or want to develop provisions, then I specifically do an evaluation. The D-G constructs instruments that permit this evaluation and then looks at the data and forms a conclusion on what needs to be changed and justifies what needs to be created. We try to do this, to build that bridge and use resources effectively. (Informant for SA)

District centres also have the responsibility of evaluating and supporting private institutions that have partnerships with the state. They have a similar relationship to institutions as schools have to children. If an institution or its protocols need to be developed or changed, then that is done via the ISS and the SA. The SA takes the normative/technical approach in creating the tools for the development and evaluation of these circumstances, and the ISS usually takes more of an implementation role:

We are part of one of the central services, the ISS, and therefore do not work directly with the public. We have an intermediary role supporting the activities of various services of social security located in the 18 district centres throughout the country. These district centres have local services, and those local services are closest to the population. There are specialists that work directly with the population. At this moment, it is felt here, and in the field of disability, which is incorporated in our activity plan, that our functions are of supporting and following these services. This is in form of reports with guidelines for these services. We also in the context of creating instruments that facilitate the conduct of policies that need to be implemented, because these policies are implemented by the teams that are working closer with the population. We also evaluate the policy implementation measures ... some of them. We also participate in training of those teams. (Disability Specialist)

Whilst the SA formulates and disseminates policy guidelines and legislation, the ISS supports its dissemination and implementation at district level. Within this context, the ISS takes a more personalised view in guiding policy implementation and supports local services and districts in structuring their provisions. Like the informant for the DREL they target institutions that work with the public rather than the public itself. Although they take the interests and the welfare of the public into consideration, their main priority is to equip and educate street level bureaucrats to fulfil that role. Hence, the needs that these individuals are identifying and addressing are those of people working with children with disabilities, rather than children with disabilities themselves. This approach was also observed within written legislation and seems to be a predominant theme in the structure of policies orientated at children with disabilities.

In terms of the relationship of the ISS with others, the Children's Specialist further added:

Exactly and the ways of training are distinct to the way the systems plan to approach the subject, but also with the logic of knowledge transfer and methods of work so that they organise the intervention so that the teams can organise their intervention with groups such as disability, so that there is a systematic approach close to the child and also the families. Aside from that, here at ISS, we participate not only in the elaboration of guides and manuals of procedure and not only, and we also in the area of disability, work with other entities such as the D-G, SNRIPD, and also in the employment, professional and training sector, also when any issues in this area emerge, these issues are taken into consideration and are worked on in work groups in order to create documents that reflect this necessity and reflect some of the problems that are felt by the specialists in the direct intervention. With this relationship that we have with the frontline specialists, we have a list of needs and proposals for their tutelage. We are the link between the direct intervention and the political decision. (Children's Specialist)

As highlighted above, the ISS is a nucleus of information that transfers knowledge and trains entities in their work, conduct and service provision. In addition to working with district and local services, the ISS also works alongside other D-Gs, especially the DGSS and, within the field of disability, the SNRIPD as well as other sectors. Work groups were often mentioned as a common practice. As stated above, when issues arise that are interdisciplinary, inter-ministerial or multidisciplinary, teams are formed in order to tackle these issues and form comprehensive solutions. ECI is a prime example of that, as it not only covers social security, but also education and health. The ISS tutors the specialists in implementing policies. They are the nodal point for putting policy into practice. Before elaborating this point further, the private-public approaches shall first be discussed. The following section will explore the relationship between the public and the private sector in the light of the interviews.

7.5 Private-Public Approaches

Yes. We work with all the NGOs in Portugal that have special schools and we have agreements with all of them. All that is CERCI, IPSS, Leagues, we have agreements with all of them. Yes. We have a great partnership with all those NGOs. For example, this Program of Sign Language is being done with the Deaf Association. We have a consistent network that works in a positive cooperation. A very positive cooperation. (Informant for SNE)

The informant for SNE painted a very positive picture of the relationship with non-governmental organisations and agencies. Although she did not seem to want to elaborate on the details of this cooperation, she kept insisting how positive and effective it was. FENACERCI is a popular organisation within education and

disability policy. Most of the interviewees in the civil service mentioned their relationship with them and their role.

Whether it be in schools or institutions each child.... It's like this. If mainstream schools does not have conditions, in terms of human resources and material resources, to have this child in the school, in a mainstream school that exists nationally. If the school does not have the means to support, it organises and there is legislation to support this, organises a process. In that process there is the educational plan of the student. ... there is the coordination team of educational support, that are going to give a report about it, and this school where the pupil is, asks for, in accordance with the responsible person for education, directed to an institution of special education. A CERCIS or a school. We here in the Directorate General, evaluate the process and give it positive or negative feedback. If it is positive, for those institutions like CERCIS, the student shall go there and we pay the institution. If it is a school we pay x amount for the teaching, transport, food, so there is an x amount, and it is not here in educational support that does that, it is our financial support. In the case of CERCIS, besides of all of this, we pay teachers, so we send teachers there for every 5 children, as well as paying psychologist, occupational therapists, speech therapists, support staff, so everyone in terms of human resources we pay to support these pupils. Let's say that to schools we don't pay, let's say schools that are private entities that are profit-making, CERCIS is non-profit making so we give them this funding. (informant for DREL)

As highlighted above, a CERCIS is an organisation in which the government invests heavily. As stated above, non-profit organisations that offer special education receive the full backing of the civil service. The informant from the DREL also specifically highlighted the relationship between her department with the CERCISs. She stated that organisations such as the CERCISs receive more funding, as they are non-profit organisations. The state pays for all the human resources, as well as transportation and food provided in these institutions. When asked if the resources available are enough to meet the needs of the public, she said that they were not. This perception is very different to that of the informant of SNE who said that everything that is needed was available and that all people have to do is ask in order to receive the resources and services they requires. She also stated that sometimes people want more funding and support but that too many provisions is perverse. Hence, indicating that she felt that organisations requiring support are not being appreciative enough, and perhaps are ineffective at implementing support. The informant from the DREL reiterated the existing legislation above and highlighted what it states her role is. Her main role is to assess whether cases reported to her of children requiring additional support, and decide whether the children in question need support within schools or to be placed in a special school setting.

The informant from FENACERCI also mentioned the relationship of his organisation with the state and how it impacts on their decision-making and provisions:

We always work in conjunction with the state. Who does the policies is the state, the organisations have to move around them and adapt them to the local activity. Always respecting. I can't contradict the policies of the state. Because then the state doesn't pay. So you see. We have to adhere to the policies and the state promotes them, and then have to regionally adapt to those policies. What I mean is giving employment, imagine. It is evident that I, having a small number of businesses in this region, I can't give the same approach that there is in Lisbon where there is 500 businesses, isn't it. The type of program that is applied in Lisbon is applied here. So we, let's say, have the same weapons, but they have more businesses and we have less. For example, the local policies and policies of the region are just one, but the way in which we apply those policies can vary in the creativity based on the capacity of the specialist and even in terms of the credibility of the organisation. (Informant for FENACERCI)

Boaventura Sousa Santos (1994) highlighted that civil societies have an isomorphic relationship to the state. The level of state intervention defines the extent to which civil society exists, as civil society attempts to fill the welfare gaps left by the state. In the case of Portugal, the state endorses and depends on civil society. The consequence of this is that the one cannot function without the other. They are interdependent. However, the relative autonomy between the state and civil society results in a shortfall in provisions and instability between the two as they may not complement each other. The informant for FENACERCI mentioned that, within his organisation, they adopt the policy orientations set by the government and the state. This is not because his organisation feels a strong link to the state but, rather, because this is the only way of securing funding. Hence, FENACERCI fills in the welfare gaps left by policies already set by the government, and not necessarily inequalities or gaps identified within society. This could result in the type of shortfall identified by Sousa Santos. In addition, FENACERCI exercises a certain degree of flexibility in their provisions, tailoring them to what they perceive is necessary. This may result in the instability that was highlighted by Sousa Santos, since the independent organisations will not always agree with state policy.

The informant for FENACERCI highlighted that there were various pieces of legislation that he felt were outdated and/or counterproductive:

Sometimes the policies that are imposed on us are not part of our activities. In terms of vocational training that is clear. There are complementary policies that are no longer of use to the objectives of practice. They are maladjusted. For example in the area of residential care and occupational support it's the same. The policies that are defined by the government, do not serve the interests, neither of the organisation nor of the people they serve. We develop proposals and we advise on policies and so forth, you see. Of course, the fact that we have the policies does not mean that we agree with them, at the moment there is a strong movement against policies and support to vocational training of people with mental disabilities because they have extremely aggressive agreements which conflicts with the quality of services, and we are protesting against that. The state does not pay fully the interventions we make it helps, it pays a part of the whole cost that we pay. Then the organisations have to look to other forms to pay the part that the state does not pay. The state never pays the entire cost of intervention. So then we have to look for other means of doing it. And this sometimes is worse in some areas than others, because it depends on the capacity that the organisations have. So areas like education is complicated, we are talking about families that don't even have means of sustenance, then to compensate they contribute to special education, and sometimes this is expensive for our organisation. Other areas are more simple. The area of vocational training as it is an area funded by the Europe, the issues are less serious. (Informant for FENACERCI)

There seemed to be frustration on the part of the informant about fulfilling policies when the state only partially funds their implementation, especially where he did not agree with them. Furthermore, some areas are more popular than others. Vocational training and employment-related provisions attract a lot of funding, not only nationally but also at the EU level. Education is apparently a less attractive policy area in terms of funding, perhaps this is because education is already provided by the state. Although the state does partially fund a lot of the special education related programmes within organisation such as the CERCIS, this funding and support, according to the informant for FENACERCI is not enough. As stated by the informant for FENACERCI, many of the families who have children with disabilities cannot afford to support themselves, let alone their child. The only support they get is in the form of special education, which is not enough. It does not cater for all other dimensions of the family's life. Programmes such as ECI and special education are costly, especially because they involve different specialists and multiple resources. The informant for FENACERCI did state that the government has striven to incorporate international measures and standards and to develop policies accordingly. However, he also stated that these measures are not sustainable for the Portuguese state, which simply cannot afford to implement them. It was interesting to get the perspective of the informant from FENACERCI, as the informant for SNE painted such a positive yet limited description of the public-private partnerships. The latter did state that support was provided to institutions that cater for special

education, but as stated by the informant for FENACERCI, this usually depends on whether they provide the educational measures approved by the state. Furthermore, the informant from the DREL stated that although the resources available are insufficient, the civil service has been very generous towards institutions such as the CERCI in terms of funding and support. CERCI, however, do not feel that this support is supporting enough.

In terms of social security there was not much mention of the relationship with the private sector, aside from what is given above. In the area of Social Action, in particular, the state has agreements and funds organisations that have certain services and provisions that the state is looking to sponsor. This process is similar to that mentioned by the informant from FENACERCI. In addition to funding, the ISS also provides additional support.

We have elaborate vocational training and actions for qualifications, whether is it the qualifications of the services of institutes that cater for children with disabilities, or the provisions they offer, we take part in that. Whether it is one-off or continuous training, or by supervising the teams and cases also, we work a lot on qualifications and qualifying entities in our services. (Disability Specialist)

The ISS also provides training and supervision services for the organisations and services they supervise. Theoretically this should ensure a coherent policy structure throughout the private and public sector, however, as noted by the informant of SA, this may not always be the case in practice. From what was understood from the interviews, those requiring training and information usually have to seek it out. Furthermore, because there are no comprehensive inspections for evaluating all the services available on a constant basis (rather than when a particular problem is flagged up) then it is hard to monitor who needs what training and supervision. This is a limitation noted within the field of social security mainly, although that is not to say that education does not have the same limitations. It may simply have been the case that the informants in the field of education were simply not as upfront about them. In addition, it is important to note that the informant for the SNRIPD has stated that her role is similar to that of the informants for the ISS. She too is a nodal point

for policy and practice regarding children with disabilities. This can prove quite problematic if two separate entities are performing the same role.

7.6 Concluding Remarks

IT focuses on how different roles or set social structures are identified and taken on by the individual. Through the process of identification with different sets of structural identities, each individual constructs a particular identity for themselves and, in so doing, reveals their uniqueness. Hence, it explores how the individual operates within the society in which they are situated. In contrast, SIT focuses on how the individual views themselves and how they associate themselves with a particular category and/or group. The individual, through a process of self-categorisation, enters a process of depersonalization by placing him/her within a group or global category. Through this process of depersonalization, the individual becomes part of the same group or category as other individuals, resulting in them surrendering their uniqueness. Thus, these theories support Jenkins's (1996) illustration of identity having a contradictory definition. Jenkins's example illustrates that these theories are similar in certain respects and share many common assumptions. According to the two theories, one can form an identity in a multitude of directions, whether it is from global to individual (IT) or individual to global (SIT). Respectively, identity can manifest itself in terms of personalisation, where distinguishes oneself individually in a general setting, or depersonalisation where one individual identifies with a general category or social group.

Hogg *et al.* (1995) stated that SIT does not discuss roles, as such, but it considers them when referring to intra-group dynamics. They place a great emphasis on group dynamics in defining identity and conduct. Although they do touch upon the impact of roles in the group context, there is a preference to acknowledge one's role as a 'position' within a group rather than as a role as such. They criticize IT for not taking a socio-cognitive approach and for its belief that self-definition emerges from role identification rather than the self. Their analogy of one occupying a certain position within a group rather than performing a certain role, attributes a status to the individual, but ignores the conduct resulting from having this position. Only when

linked to group norms and membership are one's behaviour and attitudes assessed. However, having a role entails a preset code of conduct and a set identity associated with that role. This identity and the role it entails is unique to those who possess it.

In terms of this thesis, when researching informants' identities in the work place, and how it impacts on decision-making, it is important to take into account what their role is. Thus, a combination of SIT and IT is more appropriate in tackling these research objectives than either of these theories alone, especially when it came to analysing the interview data. Each theory was not sufficient on its own, providing only a patchy analysis. The interviewees did not only categorise themselves, but also identified roles. By combining the two theories, one can not only explore who an individual believes they are, but also their actions: the active and the socialised self. Furthermore, it could be an effective tool in researching the policy process by unmasking the core of the decision-making process: the decision-maker. Stets and Burke (2000) advocated this fusion of who one is (SIT), with what one does (IT), and that this fusion is beneficial to the field of social psychology at all levels:

...one's identities are composed of the self-views that emerge from reflexive activity of self-categorisation or identification in terms of membership of particular *groups* or *roles*.
(Stets and Burke, 2000: 225-226)

The process of depersonalization through self-categorisation is very much similar to that of role identification. Furthermore, having certain self-conceptions and identities entails acting and reacting in a certain fashion. As Stets and Burke indicate, the theories are substantially more similar than is often believed. Role identification too, suggests an inter-group approach, but from a reciprocally interactionist perspective. Rather than breaking down surrounding structures into in-group/out-group statuses, role identification explores the relationship of the individual with the surrounding social structures.

There is an ongoing debate as to the effectiveness of Identity Theory and Social Identity Theory in defining identity. In an attempt to find a working definition and/or theory applicable to professional or work-based identity, this chapter applied these two theories to analyse the interview data collected from key decision-makers in the

Portuguese disability policy process. This chapter focussed mainly on the informants' job descriptions. It emerged that, in terms of professional identity, the informants employed processes identified by both IT and SIT to define themselves. Although IT processes were more predominant, this does not mean that SIT is a less valuable theory, since one's job entails preset roles and responsibilities.

According to the interview data, professional identification tended to emerge not only from one's current job and/or workplace, but also from past jobs and career paths. Only when role-identification took place did work-related roles come to the fore. Generally, higher level civil servants (i.e. within the Directorate-Generals) tended to have a techno-normative identification. They formulate and disseminate policy to top level civil servants who implement them. Their only interaction with street-level civil servants and the public is through the reports that are passed onto them. Therefore, it is rare for these entities to interact with street-level issues. They also work closely with the government and, as a result, were concerned with the policy process. As a result, their priorities do not necessarily reflect the public's need, if at all, but rather the priorities of the government. Those in senior managerial roles tended to distinguish themselves as individuals rather than part of a collective, by referring to their individual role and category. However, this was not exclusive to this group. The Informant for Regimes tended to view herself in a more identitarian perspective; meaning her social and political action is powerfully shaped by her position within her work and social space (Brubaker and Cooper, 2000), that is to say the roles she adopts rather than the way she categorises herself.

The most interesting interview was that of the respondent from the SNRIPD. This is due to the structural factors that surrounded her. Not only was she relatively new to her post, which resulted in her identifying with her previous professional experiences, but the SNRIPD itself has had an unclearly defined role. Her department keeps changing tutelage and ministry, rendering it an unstable post within the civil service. This possibly resulted in some form of autonomy and perceived detachment from any of the structures within the civil service. In fact, although the SNRIPD has mostly been within the area of Social Security, the

interviewee from this organisation identified more with the field of education as they shared similar ideals. Furthermore, because the informant from the SNRIPD has a similar role to that of the informants from the ISS, it would be interesting to view the areas of responsibility for each entity and whether these overlap in any way. The policy area regarding children with disabilities is vast. By viewing who covers what areas, one can, therefore, identify what areas are being overlooked. This shall be discussed in the chapters to follow. The lower level civil servants tended to focus on areas that needed to be addressed. These areas could be issues that emerge at street level, or priority areas highlighted within policy and legislation, but still with the public's needs at hand.

FENACERCI and the APD had differentiated views about the state. FENACERCI tended to cover policy areas dictated by the state since this was the only way they could secure funding. Although the informant from FENACERCI highlighted his intent on providing extra services to those sponsored by the state, funding was not enough, especially because he feels the funding he gets is not enough. Although he does to a certain extent feel autonomous and independent from the state, from the interview it appears that he is confined to the policies the state advocates. In contrast, the informant from the APD campaigns to get services and provisions not covered by the state and, therefore, feels fully independent.

Carroll's (1993) analogies of experience equating to more detailed and fewer schemas was reflected by the responses given by the interviewees. Those who have had their job for longer displayed a clearer and a more detail understanding of what their job involved and, hence, who they were within their work Place. Interestingly, the informant for FENACERCI kept referring to himself as a teacher rather than the Vice-President of FENACERCI. Similarly the children's specialist at SNRIPD went over her background in some detail before tackling what her job was. This illustrates how these two informants have an array or diverging schemas associated with their job. Both informants needed to elaborate on different identities they have regarding their work and underwent an identity transition until reaching the definition they were most comfortable with. As result, it can be viewed that one's current job does

not necessarily equate to the identity one has in association with that job. Previous work experiences may have more of an impact on one's professional identity than their current job and this, in turn, may influence the decisions one takes within this job.

Each of the informants cited above work within an organization and thus work within a team or in association with other individuals. Hogg and Terry (2000) argued that it is possible to find a prototypical in-group identity within the workplace. The informants in non-managerial posts tended to view themselves as part of a team rather than as an individual. However, the informants in managerial positions also have identified groups. In terms of the D-Gs, the representative for SA elaborated how she sometimes works with individuals from other D-Gs to elaborate policies and welfare measures. The representative for IR within the same D-G highlighted her ties to the UN and her ties with the European Union, as well as social security specific associations and institutions. Similarly, the D-G informant for SNE has worked in collaboration with the European Agency for Development in Special Needs Education and has touched upon her association with this group, as did the informant from the SNRIPD.

In addition, the informant from the SNRIPD felt closer to special education, as she identified more with the issues and procedures within that area. These results suggest there is an identification with groups that are outside of the workplace, which is imperative for networking and collaborative work. However, there is a downside to this. One could identify more with groups outside of the workplace than inside. There seems to be a hierarchical distinction between the different informants. For example, in-group identification at D-G level seems to protrude more according to tier or job type, as opposed to field, whereas other informants identify more with their previous jobs. This, coupled with the OECD's (2003) observation that there is a lack of communication and coordination between tiers of government, could account for erratic policy provisions and outcomes. Furthermore, this lack of identification or rather out-group identification between tiers could result in distancing and thus the lack of communication and coordination, where certain areas may be overlooked. In

order to explore this area further, the following chapter shall explore the policy areas directed at children with disabilities. It shall explore the policy areas that each interviewee covers and whether or not they overlap. It will make the link between professional identity (the self) with the policy structure in which the interviewees operate in.

8. Identifying with Children with Disabilities in the Policy Context

8.1 Introduction

This chapter explores how each of the interviewees understood the term 'children with disabilities.' The previous chapters have explored how each of the interviewees constructed their professional identities in the context of their job and also the policy structure surrounding their work. In contrast, this chapter focuses on how the 'self' views the 'other'. Only one of the interviewees has a disability themselves and none of them are children. Consequently, most informants do not share experiences with the social group with whom their work is related. This chapter aims to explore how the interviewees identify with children with disabilities and, moreover, how this identification reflects on and influences policies regarding the needs and welfare of children with disabilities.

The term 'children with disabilities' incorporates two overlapping social groups: children and the disabled. Whilst children with disabilities share the experiences of both these groups, these experiences combined represent a unique experience particular to disabled children. This was clearly reflected within the interviews. The literature review chapter reflected on varying ways in which children, disability and children with disabilities can be viewed and understood. This chapter is structured according to the different approaches to childhood and disability set out above. Following the data analysis, it was found there are several thematic approaches to disabled children that arose: children and impairment, children with disabilities and children as dependents. As a result, this chapter shall start by exploring these three categories in the context of the theoretical frameworks presented in the literature review.

In addition, this chapter shall also introduce the results gathered from the vignettes introduced in the interviews. The vignettes aimed at exploring the unconscious beliefs of each interviewee regarding children with disabilities and the associated policies and provisions. As well as the active responses associated with the

information above, this chapter shall also explore the unconscious responses elicited by the vignettes and examines whether these responses differ from the active responses from the interviews.

8.2 Children and Impairment

There was a tendency within the interviews to group the term ‘children with disabilities’ with other social groups. When first asked, the respondent for Social Action (SA) stated that ‘according to the UNCRC a child remains a child until 18 years of age’ (Informant for SA), illustrating that this respondent identified a child with disabilities first and foremost as a child rather than as a disabled person. The informant from the Portuguese Association for Disabled (APD) offered the following definition of children with disabilities:

It is a person that is a minor, or better, that still hasn’t reached the age of puberty, still is not a young person. More-or-less under 14 years or 12 years, I don’t know, that has some form of disability or has a combination of characteristics that distinguish him/her from the set prototype of normality. (Informant for APD)

As mentioned above, in the section on professional identity, the informant for the APD has a disability himself. Consequently, this respondent lives and experiences the barriers confronted by disabled people which the APD fights against. His identification of children with disabilities occurs through his own personal experiences. This informant was the only informant to clearly delineate the difference between a child, on the one hand, and a young person, or teenager, on the other. Furthermore, this informant highlights that a child with disabilities is a child that does not fit into the norm or is not viewed as being a ‘normal’ child. Perhaps these sentiments of not fitting into the norm are born out of personal experience. However, there were other informants who took a similar view from a non-disabled perspective.

As was seen in Chapters 5 and 6, within written policy, young people are perhaps the only group that is in fact identified in policy documents. Although the majority of the respondents identified children with disabilities as an all-encompassing term from covering those aged between 0-18 years, existing laws suggest a distinction between

children too young to work and those at working age, referred to as young people. This identification extended to those with disabilities. These policies did not suggest an age regarding young people, but rather listed a series of measures linked to employment. In fact, children were hardly mentioned within legislation and policy plans, except when it came to cash benefits, education or in particular circumstances, such as children at risk. Similarly, the informant from the APD listed the independent living movement as his main priority in terms of raising awareness. Clearly, this is an issue that is of interest to adults with disabilities. By having an institution run by adults with disabilities, the issues that that institution will essentially tackle are innately relating to adults rather than children. Although these issues are of interest to children in the long run, in the short run children's issues are not being addressed.

Look. So a child with disabilities... What comes to mind is a child that has a handicap at a physical or sensory level. After that will translate to that which we regulate as a visual impairment, hearing impairment, motor impairment. Therefore we have to... There is a handicap whether motor or sensory that in the end makes that child different, isn't it, from the others. (Informant for SNRIPD)

The question of how one perceives the category children with disabilities, proved to be the most difficult issue to resolve. The majority of the informants struggled to do so and required prompting. For example, when asked, the informant cited above required some prompting as to how to answer the question. As a result, she was asked what comes to mind when she hears the term 'child with disabilities'. Automatically, this question must have triggered a visual image of a child with a visible disability of a sensory or physical nature. This informant also went on to highlight the recent appearance of mental impairments which are not as visible. The informant for FENACERCI too highlighted this distinction which shall be discussed further in following sections.

However, it is important to note that the informant from the DREL highlighted that these visible disabilities resulted in a child being different from the others. From a schematic perspective, this respondent does not have a disability herself. She has been a teacher and now works in the Regional-Directorate for Education in Lisbon in the area of Special Needs Education (SNE). Perhaps because children with

disabilities have additional needs, they are seen as different as they require specialised support that non-disabled children do not need. Furthermore, not being disabled herself, she has no direct, personal experience of the challenges facing disabled persons and, therefore, views those who are disabled as being different to her. This is not to say that this difference is malicious in content, just that a distinction was noted between the appearance of disabled and non-disabled children.

Titchkosky (2000), in reviewing the transition of 'disability' from old to new, drew on Goffman's (1969) work on 'stigma'. She takes Goffman's conception of the *normals*: those who have certain expectations of how things should be and stigmatise if their expectations are not met, or if someone differs from their expectations. In these studies, both Goffman and Titchkosky take the relativist stance that the concept of normality is unique to each of us and that we all play the role of the *normals* in our own conceptions of the world. The important thing, however, is to keep an open mind about those who differ in some way from the norms. In terms of disability, the interviewees associated certain attributes with disability on the basis of their knowledge and personal experiences. Titchkosky (2000) noted that one of key types of stigma reflected throughout Goffman's work was the 'abomination of the body'. This form of stigmatisation illustrates the experience of disability by the non-disabled as 'interactions with people whose bodies are an abomination to the normals' sense of the normal body' (Titchkosky, 2000: 205). As elaborated above the respondent from the DREL automatically highlighted visible disabilities when asked to define her perception of children with disabilities. Only later did she go on to discuss mental impairments. She also described children with disabilities as different, perhaps because they have different characteristics to the *normals*' sense of the normal body. A phenomenon highlighted by the APD's informant.

However, not all informants responded in this way. The respondent for International Relations (IR) took a more inclusive approach to defining children with disabilities. She highlighted that a child with disabilities was a child like any other, as is illustrated below:

I think that a child with disabilities is a child that has some difficulties, and has abilities like any other child but, then, also has some limitations. One or many limitations, but has like all the other children a combination of abilities that all children have. (Informant for IR)

When first asked how this informant perceives and defines a child with disability, she automatically highlighted that she is not a specialist. Furthermore, being one of the less specialised respondents within this area, she took a more personal stance on her definition of disability. Interestingly, this informant also works with the UN, but has not really reflected directly upon the principles that the UN upholds regarding disability. However, she opted for a diplomatic, albeit genuinely egalitarian, view of children with disabilities, especially in comparison to children in general.

There were other informants who took a very direct professional approach to defining disability. The children's specialist in the Institute for Social Security (ISS), for example, defined children with disabilities with the paradigm of her work:

I work most of all with children at risk. Therefore, I have a systematic and global perspective on this matter. So, basically, in the matter of disabled children, I see them as a child that has specific or special needs that are derived from that situation. (Children's Specialist)

This quote suggests elements of both the social and medical models of disability. In viewing a child with disabilities as a child that has needs specific to a given situation, one must pay attention to what that situation is and not just to the child. If we take the concept of 'situation' as referring to the environment of social context in which the child is situated, then this informant is taking the view that disability is very closely aligned with the social model of disability. However, if this informant means that the 'situation' in which the child finds themselves equates to their impairment, then this reveals a medicalised view of disability. The informant above was, in fact, referring to both the impairment itself, and also to the context the child is situated. This results, as she put it, in an 'bio-psycho-social' perspective. By understanding and embracing impairment from the perspective of the social model, then provisions and changes can be made to overcome the environmental barriers to a child's integration. For those such as Finkelstein (1993) or Morris (1991) who argue that there should be a commonality of disability, this approach equates to a highly individualised and medicalised way of viewing disability, since it situates disability

with the impairment itself. However, as Crow (1996) argues, we should embrace impairment in tackling disability. The ‘commonality’ approach advocated by Finkelstein and Morris suggests that disability is exclusively social (Low, 2006), which is not entirely the case.

The informants above seem to support the latter position, by viewing disability in a bio-psycho social light. However, as noted above, this view is adopted in the context of children at risk and, as previously discussed, the perception of being ‘at risk’ and the needs related to this may override pre-existing perceptions of children with disabilities and their particular needs. The informant, in collaboration with the disability specialist for the ISS, mentioned that a child's needs change with time. Throughout the developmental process, the situation in which the child finds themselves changes and, consequently, their specific needs will differ.

8.3 Children with Disabilities

The informants from the ISS specialise separately in issues relating to the two main social groups into which children with disabilities fall: children and people with disabilities. When asked what their perception was of children with disabilities they exercised their professional identity; they conceptualised children with disabilities in the context of the area they specialised in. The children’s specialist outlined how she mainly focuses on children at risk, and would approach the term ‘disabled child’ in a similar fashion. What are the risks that place this child in a situation of risk. On the other hand as depicted above, the disability specialist views a child with disabilities as a person with disabilities at a particular stage of her or his life.

For me the concept of disabled child, well I have some difficulty in talking about children with disabilities. For me it is easier to think of disabled person, because it is a condition that one has at that moment of time, and that can be altered, and obviously, the issue of being a disabled child this implies that the work, the technical intervention that targets the child and their family is more demanding than that of any other phase of life, in adult age or even old age. (Disability Specialist)

As highlighted above, viewing children with disabilities as persons with disabilities may result in children's specific needs being overshadowed by the needs of disabled adults. Aside from ECI and family allowances, the only other direct reference to

children with disabilities in the relevant policy documents is to young people and most associated policies relate to employment and vocational training. Between these two specialists from the ISS, there is a substantial difference in priorities, with one focusing on children at risk and the other on people with disabilities. In this context, they run the risk of not identifying the other needs that children with disabilities may have and the rights they should be entitled to.

I do not see children with disabilities as disabled. I think the cataloguing the disabled is abusive. A so-called 'normal' person can be disabled for not knowing sign language or a foreign language when they are in the respective country. (Informant for SA)

As mentioned previously, in adopting the social model of disability, one could argue that those who have limited skills could be seen as disabled. This analogy has been noted by the respondent above who specialises in measures within the area of Social Action. Interestingly, this respondent took a similarly egalitarian and diplomatic approach to that of her colleague responsible for IR at the DGSS. She highlights that disability is a question of barriers, such as language barriers, and that, because disability is situational in nature, anyone can potentially be disabled. However, she did refer to someone without disabilities as 'so-called normal.' Although she tries to distance herself from the comparison of disability with normality by inserting the phrase 'so-called' into her response, she still makes a distinction between people with disabilities and those without disabilities, whereby people without disabilities are perceived as the norm. A similar phenomenon is observed in Stalker *et al.*'s (1999) study of social work organisations, in which they found that although people believe they prescribe to the inclusive, social model approach to disability, they do not act accordingly, and a discourse of normalisation remains the standard approach to these issues. This seems to be the case with the interviews conducted within the context of the current project. Although some interviewees seemed to identify more with the social model of disability than others, they didn't always follow this model through. For example, the informant for SA commented:

In terms of perceiving a child with disabilities I will highlight a few areas. One is pregnancy and birth, where one can do medical tests to detect if the child has a disability. Sometimes with the assistance at birth and how it is executed can lead to disability. Some years ago 50% of cerebral palsy cases were the result of negligence at birth. Following a child's

development, for example, early childhood intervention (0-6 years), namely a doctor can identify if a child has a disability. In early childhood intervention, for example, the child normally is with the nanny or a crèche or the family, these too can diagnose or see if there are difficulties in the development of the child. (Informant for SA)

The informant for SA did go onto highlight how impairment leads to disability, and that disability is usually diagnosed by doctors, suggesting it is also a medical issue. This illustrates this perception that one is already considered to be disabled because of a specific impairment even before the environmental and social factors are taken into consideration. Although this informant, as highlighted above, is trying to present a politically correct and up-to-date perception of disability, she still retains an essentially medicalised view and focuses on the difficulties and limitations that children with disabilities have. Although the term for disability in Portuguese is ‘abusive’, her perception of disability remains situated within a discourse medicalisation and normalisation.

Chapter 5 highlighted Barnes’s (2003) argument that certain countries have difficulties grasping the implications of the social movement due to the differences in language associated with disability. The interviews were conducted in Portuguese and the term for disability in Portugal is ‘*deficiente*’ (deficient). Having explored the definition of disability in various dictionaries, both Portuguese and English, as well as translation dictionaries, words such as ‘faulty’ or ‘lacking’ always come up in relation to disability. In contrast, ‘disability’ according to the Merriam-Webster dictionary refers to:

incapacitated by illness or injury; *also* : physically or mentally impaired in a way that substantially limits activity especially in relation to employment or education. (Merriam-Webster online, 2007)

Although this latter definition still retains elements of the medical model of disability, as it highlights disability as resulting from an impairment, it does have a less derogatory element. Therefore, when the respondent for SA refers to disabled people, she is referring to people with disabilities as being in some way ‘deficient’. This element of deficiency could also be the basis for the notions of pity mixed in

with invalidity identified by Oliveira (2004) as being associated with people with disabilities within Portugal

However, deficiency is not the only alternative term to disability mentioned in the interviews. As elaborated in Chapter 6 the DREL respondent used the term 'handicap,' which is slightly outdated and no longer considered to be politically correct. Oliver (1996) commented on the impact of language, arguing that the problem is not words as such, but the meaning and reality we construct with them. He took the WHO's 1980 classification of disability as an illustration of this process in action. According to this document, impairment leads to disability and disability, in turn, leads to handicap. As a result, handicap reflects that medical/individual model of disability, being the result of an impairment, and can be seen as the direct opposite of the account of disability advocated by the social model. However, recent changes to the classification by the WHO have rendered the term 'handicap' outdated. This new classification places impairment in a social context, assigning the responsibility for disablement to a variety of factors other than impairment. Nonetheless, as discussed in Chapter 4, Barnes (2003) highlighted that the ICF can also portray a medical picture of disability as it does not suggest or provide effective tools to measure and monitor environmental factors that may be disabling.

Various interviewees mentioned the WHO and the current classification of disability as being of importance in defining and considering disability. In fact, when conducting the interviews, the Portuguese version of the ICF had recently been published in Portuguese and was in the process of being made available to the public. Consequently, although the informant from the DREL may still have been using the outdated terminology, perhaps this informant is aware of the importance of the WHO's classification. However, as was discussed in Chapter 4 this interviewee may have used the term 'handicap' because of terminology adopted by UNESCO (in certain cases), which is a leading influence on educational policy in Portugal. Furthermore, being unable to speak English and speaking to a British researcher, she may have thought she was adopting the appropriate terminology.

In the end what's at stake is that children with disabilities are always more or less characterised as stated in the WHO. These children that have or possess these characteristics need pedagogic support. Be it in the nature of pedagogic or therapeutic support, Social Security intervenes. The regimes of Social Security intervene by guaranteeing provisions of Social Security. (Informant for Regimes)

The ICF has become an important classification regarding disability and, as highlighted by the informant for Regimes in the DGSS, it is the classification used to categorise children with disabilities in this organisation. The importance of administrative categories was discussed above (see Fulcher 1989; Bolderson and Mabbett 1991; Stone 1984; Hill and Bramley 1986). They define who is entitled to what. In this case, the informant for Regimes states that the ICF is a classification used in defining children with disabilities. According to this informant it is pedagogic or therapeutic support. This again refers back to the rehabilitative approach to disability encountered in Portugal which, as discussed in Chapter 4, also reflects the WHO's approach.

We have to go a bit to the existent classifications for disability, the perceptions that exist. We have here the ICF, if we want the classification of the WHO. But it is enough to have that perception. The problem with it is that it highlights discrimination against people with disabilities, isn't it? The disability itself and the capacity it generates, produces the disadvantage. That is what is meant by intervention at incapacity level. We can intervene at disadvantage level. (Informant for FENACERCI)

When discussing how to define disability the informant above also referred to the ICF. As elaborated above, people with disabilities may have a limited capacity level and, as a result, be disadvantaged. What is needed is to intervene at the level of the disadvantage they experience, rather than at the level of the impairment. This informant states that 'disability is about the incapacity that results in disadvantages that the incapacity provokes.' This analogy is very similar to the categorisation set out by the WHO in the 1980s. There seems to be an inability to let go of the notion that impairment is the main cause of disability, amongst all the informants mentioning the ICF. Perhaps because this was the prevailing wisdom for such a long time, it is hard for one to fully understand and take on the principles advocated in the social model of disability, which represents a departure from this established way of thinking. Perhaps also, as was suggested above, the Portuguese language does not allow for this shift in thinking to occur. However, with the ICF still referring to body

structure and function, it is hard to detach oneself from a medicalised view of disability, especially when the social and environmental barriers are only taken into consideration once an impairment has been defined.

As was argued above, the more experience one has in a particular area, the stronger association there is with that area. In terms of impairment, although informants are aware of the new classification they may still view it in the lens of the former classification system. In other words, the thought processes associated with the previous 1980's classification are applied and used to interpret the current ICF classification. By retaining sections in the new classification on body structure and function, it still allows one to attribute the cause of disability to notions of impairment. In addition, as suggested by Barnes (2003), because the ICF does not touch upon viable methods to tackle environmental barriers to the full social integration of people with disabilities, which may result in these barriers being overlooked or tackled ineffectively. As highlighted in Stalker *et al.* (1999), respondents generally professed themselves as believers in elements ingrained in the social model. However, at times (and possibly unknowingly) informants displayed medical-based conceptions of disability. Although it is argued that impairment needs to be acknowledged, so should the social barriers. Disability should not be exclusively about impairment as in the medical model (see Finkelstein, 1993 or Morris, 1991), nor, however, should it be seen as an exclusively social issue as indicated within the social model (see Crow 1996, Shakespeare and Watson, 2002 or Low 2006).

In addition to impairment, the informant above also highlighted that there are certain social stigmas associated with disability that need to be addressed. Discrimination, it was argued, can be just as disabling as impairment. However, as seen in previous chapters, there seems to be a view in legislation that discrimination can be addressed through affirmative action in the labour market and, to a certain extent, by raising awareness. However, the social barriers have not really been addressed, suggesting that discrimination too has not been fully addressed and confronted.

The informant for FENACERCI went on to note that mental impairments are not as obvious as sensory or physical impairments and that they are, therefore, hard to diagnose immediately in an individual.

Here we are talking about mental disability, but we can talk about physical and sensory disability. Perceiving a child with a visual impairment is easier isn't it? Because the functional limitation is at the level of their vision and is perfectly perceptible and therefore we can immediately perceive the visual impairment, isn't it? So when it is universal when he is... Well, perceiving a hearing impairment is the same isn't it? Why? Because the child doesn't speak, isn't it? However, perceiving a child with a mental impairment is more complicated. Because it isn't necessarily immediately perceptible and can depend on our appreciation of functionalities. So what is a mental disability, as I say, a child with a mental impairment is a child that has difficulties, that has a slow development or can only do less things than others. Child with mental impairments is that one that is protected because their level of functionality has to be lower than others. (Informant for FENACERCI)

After highlighting the ICF this interviewee, like others, went back to highlighting the medical/impairment basis of disability, rather than highlighting social factors as the cause of disability. This informant places great emphasis on levels of functionality, something which is also reflected in the ICF. Furthermore, he identified himself as a teacher. As a teacher in the field of special education, he is recapitulating what the characteristics are of students with mental impairments. Perhaps in this context he is speaking as a teacher rather than a manager. It is important to note that CERCI stands for the Cooperative for the Education and Rehabilitation of Maladjusted Children (Cooperativa Para A Educação E Reabilitação de Crianças Inadaptadas) and although in English this title is translated to 'Cooperative for the Education and Rehabilitation of Children with Learning Disabilities', the fact of the matter is the Portuguese version is very different to the English version.

What is used, well, if we go to the concept of disability by the WHO, especially at the level of the recent one, the ICF, isn't it... There is an alteration to the structure of the body or function of the body. This here in relation to disability, with reference to ICF there is impairment isn't it? Now we have the incapacity from a global perspective or rather "the functionality of the child" since this child could be 100% functional if in fact they have the means to do so. So, the issue is that everything depends on the interaction.
(Informant for SNRIPD)

When asked if a child who is a wheelchair user who lived in a non-disabling environment with accessible infrastructures was still considered to be disabled, this informant said yes and responded with the statement above. This informant has taken

the notion of body structure and function from the ICF and applied a medical foundation to it. Since the child has an alteration to the structure and/or function of their body, then they are already considered disabled in the eyes of this informant, rather than concluding that they have the possibility of being disabled when considering all the surrounding factors. This respondent goes on to highlight that the child will also have to do certain things differently to other children.

In a similar vein to the DREL's respondent, this informant from the SNRIPD differentiates children with disabilities from non-disabled children. She states that children with disabilities do things 'differently'. However, just because children with disabilities are perceived as doing things 'differently' it does not mean that children with disabilities are different or 'not normal'. It simply means that children with disabilities have different needs that must be addressed regardless of the situation in which they find themselves. Within a policy context this 'disability' will always have to be identified in order to create an enabling environment.

In contrast, the informants for the ISS denied that people with disabilities would still be disabled if all environmental barriers to their full social integration were to be removed:

Exactly, no because they would have everything available. They would have services, in this they would be child, isn't it? Because the possibility was given. We were given tools necessary for him, so he can move and go to any service. Can go to the cinema... Can go to a job interview.. Can take care of his situation... Go shopping. There doesn't remain, also doesn't create dependency of those people on tertiary parties. Isn't it? From the start if the context is adequate, then the situation, the need of that person stops being confronted as a problem, and disability stops being a problematic. It's a problematic because perhaps I say unfortunately, isn't it, that society is not organised. Obviously we are progressing towards that. There is a combination of situations that in that area, but we still have not been able to abolish a combination of situations that make the life of these people into a problem. The things should be far simpler. (Disability Specialist)

The Disability Specialist from the ISS, with the back up of the Children's Specialist from the same organisation, highlighted that she believed that a person who has an impairment does not necessarily have a disability. However, it is important to note that according to this informant her definition of non-disability entails complete independence and autonomy. However, these informants did not highlight other

barriers that are non-physical, such as discrimination. In addition, they did not question or address how the barriers they did highlight would be overcome or take a stance similar to that of the informant for SNRIPD. The informant for SNRIPD argued that regardless of how inclusive and enabling society is, one will always have a disability because, in order for society to be inclusive, that disability needs to be addressed.

Referring back to the respondent from the APD and the emphasis he placed on his support for the 'independent living movement', his identification with this movement is evident from the fact that he adopts a notion of 'normalisation'. Gadacz referred to this notion as:

The value of people with disabilities able to have normal life experiences, and the focus of attention is on the ways that language, images and programs can enhance autonomy or maintain people in dependent social roles. (Gadacz, 1994: 167)

At first glance the informants from the ISS seemed the most inclined towards the social model. However, for a non-disabled adult, such as the informant for the ISS, this process of normalisation perhaps entails living in exactly the same manner as a non-disabled person. By contrast, what this process of normalisation suggests is that people with disabilities have an equality of opportunities as non-disabled people. In looking at the development from childhood to adulthood, when someone reaches adulthood they are expected to become independent and self-sufficient. In the case of people with disabilities this may not be the case, as certain impairments may need individualised support in order to overcome certain barriers. For an adult who sees him/herself as independent and self-sufficient, this idea of having individualised support may seem like a sign of dependency. This refers back to the notion of difference, because if something is not the way of the majority, then it is not seen to be right or normal. Consequently, if one needs individualised support, then one is seen to be disabled. However, this notion of dependency is slightly biased, as it can be argued that everyone needs a some degree of support at some time or other, whether it be emotional, physical or intellectual support. As a result, one could argue that everyone is dependent and has a disability or at the very least has been at some

point in their lives. Furthermore, everyone has needs that manifest themselves in different forms. Consequently, we should reassess our idea of support and dependency to develop a more pluralist and all-encompassing account of these notions.

The informant for SNE, too, gave her interpretation of disability.

Well, my perception has to do with me and not with with... A child that displays some incapacity in whatever the dominion may be. The child has needs that require a response and have to be evaluated accordingly and be given the resources they need. So that, after all, they can be happy, be successful, healthy and later on be placed in the labour market. (Informant for SNE)

As has been highlighted above, the informant for SNE takes a normalisation approach to the issue of disability. Support needs to be given in order for children with disabilities to become normal adults. As touched upon by the informant for SNE, there is a need to identify what the needs of the child are, in order to cater for them. This informant has worked alongside the European Agency and has displayed an understanding of what is going on at an international level. Every interviewee was asked if they had a personal and/or work-based interpretation or both of disability. The informant for SNE also distinguished her personal opinion from that of her workplace. However, she seems to have the same conceptualisation of disability as all the other interviewees, as well as, what is written in policy.

The informant from the DREL, who was also within the field of education, took a similar view to that of the informant for SNE, viewing disability as a condition that needs support. However, she broke the term disability down into what she saw as its main components, sensory and physical impairments, and she brushed upon the rise of cases of mental impairments:

Lately, there has been many cases of personality disorders, mainly cases of emotional problems which are also associated with that isn't it? Changing, should we say, the behaviour of a child that needs support. There, I am already things at Special Needs Education level. But now disability itself is in some form or other encapsulated within educational support in the existing legislation. They are as a result the children that show some form of handicap at these levels; mental, motor or sensory. Therefore it is within these 3 main categories. - (Informant from the DREL)

Education is one of the main areas in which mental impairments should be recognised, when regarding disabled children. As will be elaborated in the section on vignettes, inclusive schooling is encouraged whereby children with disabilities are encouraged to go to mainstream schools. As a result, there are measures in place to support children who have special needs in mainstream education. Most of these needs are associated with mental impairments, especially learning difficulties. According to this informant, impairments sector are classified into 3 groups within the education: mental, motor and sensory. Furthermore, as stated by the informant for SNRIPD, there seems to have been a rise in the number of mental impairments that have been recorded within the Education sector.

According to the Decree-Law n. 319-91 on the ‘Regime of Special Education Applicable to Students with Special Education Needs’, there was no distinction made between different types of impairment. However, there was a distinction made between disability and learning difficulties. These two categories were seen as constituting two separate groups, with the above law referring to: ‘the growing responsibility for schools to regulate for the problems of students with disabilities *or* with learning difficulties’. Hence, learning difficulties within this law are not seen as a form of disability, but rather as a condition or category on its own that requires specific educational support. Given that the field of Education concerns itself with learning, policies should be orientated at helping people to learn. This is because the difficulties that students with disabilities encounter will be centred around the learning process too. However, there are children who do not have learning difficulties, but have other disabilities. These children need educational establishments to be accessible and responsive to their needs. The policies regarding this area will be different to those of educational support for learning difficulties.

8.4 Children as Dependents

Although ‘disability’ and ‘childhood’ are the two main terms that come to mind when one thinks of a child with disabilities, other terms also arose from the interviews. The informant for Regimes, for example, displayed a strong work-related

schema, by repeating current legislation. As was illustrated by this interviewee, her department relies on definitions to make and implement policies, as their allocation of provisions is category-based. This may highlight an explanation regarding this respondent's conceptualisation of disability:

In the subsystem of social protection I do.. Here we do a framework of these articles of situations that Social Security responds at that level. So in this subsystem of family protection we have 3 eventualities: Family Allowances, Allowances in the domain of Disability and Allowances in the domain of Dependency.

In these specific situations, Social Security protects. How does it protect? Through the regimes of Social Security that guarantee subsidies and this subsidy guarantee offers the family the compensation of Family Responsibilities guaranteed to families who have a child carrying a disability or in a situation of dependency. (Informant for Regimes)

Researchers such as Fulcher (1989), as well as Bolderson and Mabbett (1991), have illustrated the importance and power of language. Bolderson and Mabbett, in particular, have commented on its use in and influence on policy. Language dictates what you are entitled to, but also defines who you are. In the case of Regimes, one can view the effects of these administrative principles. As the informant stated, they allocate provisions by virtue of belonging to a category. Children with disabilities fall into 3 particular areas that are associated with allowances or cash benefits. If you fulfil the right criteria, then you are entitled to the respective provisions. However, you are identified as being the category of disability into which you fall. According to the statement above, children with disabilities fall into 3 different categories in order to be entitled to allowances: family, disability and dependency. However, all of these categories reflect notions of dependency.

As part of her conception of children with disabilities, the informant for Regimes referred to this law: 'Regime of Social Protection of the Civil Service'.

It is considered children and young people who possess a disability, for the effect of attributing the family subsidy for children and young people, descendants of age inferior to 24 years of age, that, for motive of congenital or acquired loss or anomaly of psychological, intellectual, physiological or anatomical structure or function are found in the following situations:

Need individualised pedagogic or specified therapeutic support, adapted to the nature and characteristics of the disability that one possesses, as well as a means to prevent the deterioration, annulment or attenuation of its effects and permitting full social integration;

That frequent, are residents in or fit the criteria for frequenting or residing in special institutions of rehabilitation. (Decree-Law n. 133-B/97: art. 21)

Article 21 of the above law refers to the ‘Characterisation of Disability for the Allowances of Family Subsidies’. According to this article, children with disabilities are considered to be dependents until the age of 24. In fact, according to the Decree-Law 179/2003 on ‘Family Allowances for Children and Young People’, this allowance is granted to families with disabled children up to the age of 24. This allowance is only granted to families with non-disabled children until the age of 24 if they remain in education. Otherwise, the cut off age is 16. It is important to note that between the ages of 0-16 all children are viewed as dependents regardless of their social circumstances.

Within this article, cited above, children with disabilities are seen as descendants of the ‘beneficiaries of the regime’ (informant for Regimes). Family allowances are attributed to the family not to the child, and as the Base Law for Social Security (Law n. 32/2002) centres its policies around the family of the worker(s):

Objectives of the system

The social security system aims at carrying out the following objectives:

- a) To guarantee the achievement of the right to social security;
- b) To promote the improvement of the conditions and levels of the social protection and the strengthening of the respective equity;
- c) To protect workers and their families in situations of lack or reduction of their working capacity, of unemployment and of death;
- d) To protect people who are in a situation of lack or reduction of their subsistence means;
- e) To protect families by compensating them for their family charges;
- f) To promote social efficacy of the benefits schemes and the quality of their management, as well as the financial efficiency and sustainability of the system. (Law 32/2002: art. 4)

The informant for Regimes, found Article 21 quite outdated in its content, as she believes it doesn’t reflect the current Base Law (2002) and would, therefore, be changed soon:

In accordance with the Base Law, there would be a combination of provisions guaranteed to resident citizens in national territory, which is slightly different conception to this one which guarantees provisions only to children of beneficiaries of the general regime. So, people

before would contribute to the system, but now it isn't like that, isn't it. So, although this diploma hasn't been changed... But the concepts of disability that matter to allocate these subsidies, they are those that are dictated in this diploma still. (Informant for Regimes)

The changes that this informant suggests are that all resident citizens should be entitled to provisions, rather than just those who contribute to the system. However, as stated in the Base-Law and Article 21, the benefits system is still centred around the family. Although it may take a more all encompassing approach than before, in terms of guaranteeing provisions to all resident citizens, a hierarchy of citizens still remains. Child benefits are paid to the family, even where, in the case of children with disabilities, this allowance runs until the age of 24. Therefore, although legislation has changed, disabled children are still treated as being the children of beneficiaries rather than citizens in their own right:

It is considered people who possess a disability, for the effect of attributing a monthly lifelong subsidy, descendants starting at the age 24 years of age, that, for motive of congenital or acquired loss or anomaly of psychological, intellectual, physiological or anatomical structure or function are found unable to cater normally for their subsistence through exercising a professional activity. (Decree-Law n. 133-B/97: art. 22)

At the age of 24, the families of persons with disabilities, who are still viewed as dependents, will receive a monthly subsidy if that person with disabilities is not employed. Hence, persons with disabilities are not citizens in their own right, but their parents are. Although, as stated by the informant for Regimes, Article 22 is outdated, and until it is change, this attitude towards persons with disabilities and their relationship with the state will remain. It is important to note that an individual is deemed disabled if they are not able to work as a result of an impairment. If this is the case, why do they not receive unemployment benefits instead, and make its provision based on the ability one has to work. Although Bolderson and Mabbett (2002) stated that this would still require identifying impairment and would, therefore, conflict with certain notions of the social model of disability, it would be a more attractive alternative than the status quo. Deborah Stone (1984) highlighted that persons with disabilities are often seen as 'second-class' citizens. Similarly, Ruth Lister (1997) states that:

To be a citizen, in the sociological sense, means to enjoy the rights necessary for agency and social and political participation. To act as a citizen involves fulfilling the full potential of the status. (Lister, 1997: 35-36)

Lister highlighted a clear divide in the term ‘citizenship’. In one sense the term refers to *being* a citizen and the other refers to *acting* like one. Hence, you can be a citizen, but not necessarily act like a citizen. This distinction is obvious in the case of disability. Disabled persons have the entitlements bestowed upon them as citizens do, but do not always fulfil the attached responsibilities and obligations, such as employment. Consequently, these citizens do have the rights necessary for agency and social, civil and political participation, but they may not fulfil their full status as citizens. Disability allowances may result in the catch-22 situation described by Stone (1984), in which right to disability benefits results in justifiable unemployment due to disability and unemployment, in turn, results in second-class citizenship for disabled persons. By only having unemployment benefits, rather than additional benefits targeted at those with a disability, then everyone who is unemployed would be treated equally regardless of whether they had a disability or not. As things currently stand there are two separate groups constructed consisting of the unemployed on the one hand and people with disabilities who are unemployed on the other. This categorisation distinguishes persons with disabilities as being different from the rest of society. Why not simply have a means-tested unemployment benefit instead? In the case of children with disabilities, it is arguable whether they are even considered to be citizens. Given that the policy structures in Portugal are centred around the family, children’s political engagement and citizenship rights may be limited.

The third and final category that the informant for Regimes identified was that of Dependency, which is referred to Decree-Law n. 133-B/97:

1 – In is considered in situation of dependency, the disabled that, for causes solely attributed to disability, cannot participate with autonomy in acts that are indispensable for the satisfaction of basic needs of daily life and that need permanent assistance of another person.

2 – For the effects of the previous number, it is considered to be, namely, acts relative to nourishment, locomotion and personal hygiene. (Decree-Law n. 133-B/97: art 24)

Article 24 of the above law seems to suggest a very similar approach to that of having a dog: feed them, take them for a walk and bathe them. From the perspective of independent living, equality of opportunity in a developed country implies something above and beyond the satisfaction of one's basic needs. If this is not considered to be the case, then this article is suggesting that it is acceptable for persons with disabilities, who require individualised personal support, to live in relative poverty. Instead of focussing on one's basic needs, survival and what one cannot do, perhaps this article could be rephrased in aid of providing equality of opportunity for those who possess a disability. The recent Law n.4/2007 for Social Security has taken precisely this approach, aiming to tackle social exclusion in general rather than just catering for basic needs of people with disabilities. Increasingly, policies look to model themselves on international standards, and these, as discussed in previous chapters, are not always the most inclusive. As stated above, Decree-Law n. 133-B/97 is still adopted but, hopefully, as reflected in more recent laws, the underlying philosophy of the laws on disability will eventually change.

In terms of provisions and cash benefits, the definition of children with disabilities is quite clear cut. If someone fulfils certain criteria, then they are entitled to a set amount of money for set purposes. In the case of Social Action this may be different as it requires the providing of certain services rather than simply cash benefits. Early Childhood Intervention (ECI) is the main provision highlighted by informants with regard to children with disabilities.

3.1- Early childhood intervention is aimed at children up to 6 years of age, especially from 0 to 3 years, who are disabled or at risk of a slow development.

3.2 – It is considered to be at risk of a slow development, one who, because of pre, peri or post-natal factors or for reasons that limit the capacity of benefiting from important learning experiences, constitute the probability that one or more dysfunctions may occur.

(Joint Dispatch n. 891/99: art 3)

When asked what happens between the ages of 6-18 years, all the informants who mentioned ECI said that this was an area which required further development. The main focus with children with disabilities, aside from the benefits guaranteed to children and persons with disabilities, was ECI. ECI entails an analysis of the child's

needs and the development of a support programme to best suit the child, encompassing different specialists that follow the child's development through to the age of 6.

This is to highlight in the first few years of life, the work that is necessary to do with the family that has a child with disabilities. Not only in terms of health, as I have mentioned but in terms of integration of that child in a social response or a crèche or in a kindergarten. The more regular possible, as also understanding and helping the family create some autonomy in terms of the problematic of disability. Or also to propose to the family to learn what is the problematic of the disability. Which are the biggest problems that they can come across and also in a way discover and reorganise themselves. To discover the resources that all families have, but that can help in the development and support of this child. (Disability Specialist)

According to the specialist for Disability from the ISS, the ECI programme is almost like an introductory course in bringing up a child with disabilities. It can run until the age of 6, by which time the parents are assumed to have an idea of what their child's specific needs are, and how to best support them. In terms of social action, most policies are centred on the family and helping it to be self-sufficient. One could argue that children with disabilities are second-class citizens not because they benefit from citizenship rights without fulfilling the obligations, but because their rights and provisions are attached to their parents. It could even be said that children with disabilities, and all children to a certain extent, are not considered to be citizens in their own right but, rather, citizens by association. It seems that provisions are allocated through, and with the aim of assisting, the parents or guardians of children with disabilities. In the case of children, they could be seen as citizens in the making. However, if they have a disability, they may never reach the full citizenship status, but rather will be unemployed and hence second-class citizens.

In Portugal, six is the age at which children start school. This may be a reason why ECI stops at this age, because, in theory at least, the school should take over in supporting the child's development. However, this explanation is mere speculation, because none of the informants could provide a reason for why six years of age is the cut off point for the ECI programme. In terms of policy, a child with disabilities who needs intervention to support her/his development receives support from the state

from 0 to 6 years of age. However, a family with a child with disabilities is entitled to a family allowance until the ‘child’ reaches the age of 24.

The term ‘children’ is rarely used in policy documents in Portugal. Usually the term is only adopted when referring to children in particular circumstances that are perceived to make them ‘vulnerable’ in some way, e.g. ‘children at risk’ or ‘children with disabilities.’ Otherwise, children are usually synonymous with the dependents or descendants of citizens within policy. ‘Young people,’ on the other hand, is a term used exhaustively in policy. However, the measures associated with this term are usually orientated at integration and transition into the labour market, in addition to a few measures within social participation. Again these measures are usually aimed at equipping young people with skills necessary to integrate into the labour market. This section analysed the active responses to, and themes associated with, children with disabilities that emerged within the interviews. The following sections shall uncover the unconscious responses elicited by the vignettes.

8.5.1 Vignette Responses: Disability in the context of the ‘self’ and the ‘other’

The vignette used in this research project involved a story about a child, who has Downs Syndrome and is on the autistic spectrum. It has been recommended that he be transferred to a specials boarding school on a full time bases. He currently goes to school from 9am to 5pm, and has not been attending any extra-curricular activities due to the lack of availability. He has an emotional attachment to his mum and, therefore, does not want to go to a boarding school.

Having analysed the data retrieved from this vignette, it is clear that respondents place great emphasis on this child’s mother (see Table 1 in II. Appendix), whether they are empathising with her struggle or identifying solutions to this struggle. One may claim that there is an emphasis within the vignette on the struggle this mother has had and the fact that she has to care for her child. This, in turn, may influence the respondents to identify with the mother, as she could seem like the main protagonist in the account given. However, as was elaborated in Chapter 3, there are various

ways in which one could identify with the child directly, and respond accordingly. There are also various explanations for this preference towards the mother which shall be explored below.

If we are to look at Table 1 (see II. Appendix) we can see that the disability specialist in the ISS provided the most responses. This informant also kept changing her argument and being inconsistent with her responses to the questions asked associated with the vignette, indicating that she has not yet developed a strong schema associated with this area. By contrast, most of the respondents within the D-Gs provided short and direct responses to this scenario, suggesting they have strong schematic structures associated with this area, possibly because of their extensive experience in the field. The representatives from the ISS had worked in their field for a far shorter period of time than the representatives of the D-Gs, which could account for the ISS respondents' less direct responses. In addition, ISS respondents probably have less experience of being interviewed on this subject meaning that they did not have readily available answers to the types of issue raised. In addition, if we were to pay particular attention to the children's specialist in the ISS, she continuously makes reference to children at risk. As discussed in the previous chapter, this respondent has a longstanding association with this area and identifies strongly with it. As a result, this vignette triggered her schema associated with children at risk, as this is the main area she works in with regard to children. The representative from the DREL who has had more experience in the field than the ISS's disability representative was quite consistent with her responses, illustrating fewer, less idiosyncratic schemas surrounding this issue. However, one could argue, as a result of her interview, that her schemas are more structured round her professional experience in teaching, rather than her job at the civil service.

The vignette was drawn up in order to review the respondents' perceptions of disability with specific regard to children. In terms of the self or individual child, most of the responses were in the form of observations of the child's impairment. The respondents for SA and the DREL identified the fact that the child had a severe disability. They took a particularly familial-individual type approach, meaning that

they identified the disability with the individual and his/her family, and the responsibility for care and support lies within the relationship between the family and the individual. The respondent from DREL identified that although caring for a child with Down's Syndrome might not be more challenging than caring for a 'normal' child, the child is also on the autistic spectrum. Since this child is on the autistic spectrum, the informant for DREL suggested that he or his disability may be additionally challenging and may require some experience or additional support skills on the part of their carers. Only the children's specialist from the ISS identified the possibility of the lack of intervention so far in the family described in the vignette, intervention which may have hindered the difficulties this family experiences. These informants seemed to have a more familial-micro approach to the situation; where the disability is identified within the family and care should be in the form of local services centred around the family (see also Chapter 3).

These responses to the vignette may seem 'individualistic' in nature, but perhaps they could (to a certain extent at least) be essential to the provision process, or the identification and dismantling of 'disabling' barriers. Liz Crow (1996) stresses the need to approach and embrace impairment in order to produce a more inclusive society. In terms of disabled persons, the social oppression extends from the impairment one has which is deemed disabling. By confronting the nature of impairment, and thus the nature of the disability affecting an individual, one can overcome this disability and the 'disabling' environment within society. As Crow rightly suggests, other groups within society are oppressed by virtue of their skin colour, religion, sex, etc, which are usually not physically limiting or painful. A person with disabilities, on the other hand, is not only oppressed by his/her surroundings (as is argued by the social model of disability), but they also have to endure the physical experience of their disability. By ignoring impairment one is essentially ignoring the root of the conceptualisation of 'disability' within society.

In terms of João, the little boy discussed in the vignette, one could adopt Crow's perspective. He has Down's Syndrome and autism. In general terms, Down's Syndrome is caused by having an extra number 21 chromosome (trisomy 21) and,

according to the Down's Syndrome Association, all children who have a trisomy 21 have a certain degree of 'learning difficulties,' which vary according to the person (Down's Syndrome Association, 2008). The causes of autism are not yet known. Perhaps, in this case, it may be associated with the child's Down's Syndrome, but this is not scientifically verifiable. Nonetheless, according to the National Autistic Society, all children on the autistic spectrum are affected by what is called a triad of impairments, which affect:

- Social interaction (difficulty with social relationships)
- Social communication (difficulty with verbal and non-verbal communication)
- Imagination (difficulty in the development of play and imagination). (NAS, 2007)

It may seem that children who are on the autistic spectrum will be 'problematic' to care for, as the DREL's respondent suggested above. However, given the right knowledge and information, one can find the best ways in which to support a child with this condition such as João. As a result, in terms of suggesting alternative support programmes orientated specifically at João, there could be a number of possibilities. As Crow (1996) suggested, instead of identifying João's disability as a problem or a barrier in learning and understanding his disability, and adapting his surroundings to him, then perhaps at least one of the disabling barriers he faces could be removed.

In entering the individual-familial realm, the feeling amongst the interviewees was generally one of sympathy or empathy with the mother. Only one respondent, from the SNE, identified that it is impossible to ask more of this family and identified the lack of organisation on a micro (services) and perhaps macro (structural) level. The representatives from the DREL and the ISS, argued that the mother needed a strong 'informal' support network to raise her child. This reflects the general feeling amongst the interviewees was more orientated on the potential role of a network of family and friends rather than that of the state. However, there were brief mentions of the city council, and local authorities. All of the respondents to the vignette were female, and the majority had children. Perhaps it is for this reason that it is easier for the interviewees, who are mostly mothers themselves, to identify with and hence empathise with João's mother and the difficulties of the situation in which she finds

herself. In addition, because they suggest that João's mother carries the responsibility of his disability, to a certain extent, she too can be seen as having the disability.

As highlighted in Chapter 2, Portugal places a significant proportion of its welfare responsibilities on its domestic sphere, hence promoting the concept of familialism, characteristic of the Southern European Welfare States (Esping-Andersen, 2001). As elaborated by Ferrera (1996), the underlying familialism of the Portuguese welfare state leads to a low degree of welfare state penetration. Similarly, according to the OECD, there is limited state provision of community care services and the family is at the forefront in this area (OECD, 2003), which furthermore contributes to the ineffectiveness of welfare provision in Portugal. For example, there is no policy, as such, orientated at the family. Rather, policy is aimed at the individual belonging to a category (Portugal, 1999). In this context, it is possible that the respondents identify with the mother featured in the vignette as she is 'head' of the family, and the main breadwinner and provider for the family. Consequently, she is seen as the main protagonist in this scenario and the entity which state provision is constructed for. If we are to refer back to Table 1, we can see that most suggestions and responses are orientated at her.

On an individual-micro or macro level, one can see there are limited responses. The informant for Regimes states that João is already benefiting from what is available for him. This is perhaps true from a regime perspective, since he already benefits from the financial benefits available to him from the state, but it does appear to be a slightly individualistic response. The respondent implies that disability is an issue that can be catered for by cash benefits alone. It is an individual responsibility. From this perspective, it appears that João already benefits from all that the state has to offer and, therefore, all other difficulties are his or his family's responsibility. However, this response also highlights perhaps that the existing welfare structure is quite limited and, hence, quite limiting for the individuals concerned. If this is the case, then it can be argued that there are disabling barriers emanating from the macro level too.

The children's specialist in the ISS recognizes that ideally João should stay with his mother rather than transferring to a boarding school. This respondent, however, identifies on a micro level that the school should have more provisions, services and facilities and, on a macro level, that system of education should focus more on this area. Consequently, she highlights the barriers that are found in the structure of the education system. The specialist for SA, too, recognises the difficulties in tackling inclusion, and that special schools are not the right alternative for João. This respondent suggests that João enrolls in some form of extracurricular activity that provides transportation, and that this would reduce the amount of travelling his mother has to do in order to collect him from school. She also suggests that he should go to an ISS or a Private Institution of Social Security (IPSS), in order to retrieve information about the possibilities for extra-curricular activities which are available.

As the interviews highlight, the suggestions made by the various informants were either critical of other departments (as in the case of the ISS), or claim that they have done all that they could possibly have done. Interestingly, the respondent for Regimes seemed quite defensive about the fact that João had already benefited from all the provisions she had to offer and did not really offer any alternative. This shows a strong conviction towards what provisions are financially viable and, hence, allowed, and also an underlying conviction that the existing regime is able to meet the needs of children such as João. Throughout the interview, this respondent showed herself to be very rule orientated.

Having explored the vignette responses associated with the individual realm, hence responses centred around the child, it is now important to review the responses centred around the family and, more specifically, the head of the household and the main provider for the family. This was another theme that arose in the vignettes and shall be discussed in the following section.

8.5.2 Vignette responses: The Disabled Family

As elaborated in the previous section, it appears that João's disability has been projected onto his mother. Since he is a child and his mother is his principal carer and, therefore, responsible for him, she is seen by default as being responsible for caring for his disability. Furthermore, a significant proportion of the responses to the vignettes place emphasis on the isolation of the mother and, consequently, her inability, due to various external factors, to fully provide for her child. In the discussion of the vignette, both these individuals seemed to be treated as one entity.

Interestingly, it was those respondents who are engaged closely with implementing policy (the respondent from the DREL and the two specialists from the ISS) that noted the mother's isolation and reacted to it. These three respondents suggested that there was a need to create a social network to assist in João's care. Whilst the respondent from the DREL placed emphasis on care being provided by a social network based on family and friends, rather than the state, the respondents from the ISS did touch upon a possible network of local services. The latter, however, was not heavily emphasized. This reflects the underlying notions of familialism which underpins the Portuguese welfare state and the state's reliance on the family to provide essential services. Portugal (1996: 236) described familialism (or familism in her words) as:

a conservative ideology supported by the rural condition of a large part of the population, which permitted the maintenance of social support based on family and community solidarity and on low expectations in relation to consumption and quality of life. (Portugal, 1996: 236)

This concept, although emerging in the case of Portugal from the dictatorial regime of Salazar, is characteristic of all Southern European countries (Esping-Andersen, 2000). Generally, this concept is still reflected in today's society, as has been illustrated by the responses to the vignette. Consequently, if there is a strong family and/or community network, then this reliance is not necessarily problematic, due to these networks being able to compensate for the shortcomings of the state. However, if the family consists of a single mother and child, with no support network, then it is an entirely different matter. This highlights the problematic nature of this welfare structure. In emphasizing that the only option for this mother to improve her current

situation is to build a private social network, the respondents to the vignette clearly illustrate the shortcomings of the state. They are tacitly admitting that there is nothing they can do and, therefore, one is better off searching for private alternatives.

The respondent from the SNRIPD adds that the only option for the child is to attend a boarding school, since the community is not able to provide enough support for him to remain at home with his mother. Thus, the familialist welfare structure only works for families with a strong social network. Furthermore, it ties in with the notion of a disabled family; a family which has a member with disabilities and, as a result, encounter the same or similar barriers collectively to the person with disabilities themselves. This welfare model assumes that the norm for Portuguese society is to have a strong family/community network. This family detailed in the vignette, however, does not have this. Moreover, it is a single-parent family, which places the responsibilities for family's sustainability on just one parent. Regardless of whether this mother has a child with disabilities or not, the mother is already disadvantaged within Portuguese society (and hence can be considered 'disabled') when compared to the norm. The fact that she has a disabled child places any difficulties this child may have on the mother, resulting in a further disablement of the mother due to her child's impairment. This does not necessarily mean, however, that the disabling factor is the child's impairment rather than the structure of society and the state.

Note that when discussing João's schooling, the preferences of the child was himself were not seen to be of importance. The decision was seen as being entirely up to his mother. It was fully her responsibility. This understanding of the relationship between the parent and the child also ties in perfectly with the notion that João's mother has taken responsibility for his disability. Although there was some sympathy for João's feelings, these were not deemed to be a determining factor in deciding what course of action ought to be taken. The Specialist for Disability in the ISS, in particular, placed considerable emphasis on the option of full board at school and the fact that many parents would be grateful for this and wish they had that option. It was commented that, although the mother did not want this option, it was

what the state offered and, if she wanted a different response, she should perhaps look at other private options.

Onora O'Neill (1992) has elaborated the obligations towards children's rights. She highlights how there is a general belief that rights are assumed to benefit from perfect implementation. The right of one individual, however, generally implies an obligation on the part of someone else to ensure that right is guaranteed. When you correlate the two, the relationship isn't always a harmonious one. The requirements of João's schooling and the provision for his other needs create an obligation for the state and its policy actors to provide for both the child's and the family's requirements and to ensure the protection of their rights. However, the provisions available to João and his mother do not meet their needs or ensure the rights his mother feels they are entitled to.

The higher level policy makers, namely the representative for Social Action in the DGSSFC, suggested an 'ambulatory regime'. This regime consists of having a specialised team visiting João's house and assessing the needs of both the child and the mother before compiling a list of provisions they are entitled to and suggestions of support and services. The SNE respondent, on the other hand, emphasizes the need to have a system orientated at the citizen, which allows one to inform oneself about and claim all the benefits and provisions one is entitled to. However this provision usually manifests itself in the context of the ECI system which is aimed at children from 0-6 years of age. Unfortunately for Joao, he is now 8 and, therefore, too old to qualify for ECI.

8.6 Concluding Remarks

This chapter sought to examine how the category 'children with disabilities' is perceived by the interviewees. Knowing that all interviewees, with the exception of one, are not, and have not been, disabled, the goal was to uncover what perceptions the informants reflect onto this category. Although this category touched upon a variety of perceptions there were a few predominant themes that ran through the

interviews, which all fell under one umbrella: that children with disabilities are in some way 'different.'

The majority of respondents believed in and actively tried to portray a modern conceptualisation of disability. However, although most informants highlighted the existence of social and structural barriers that contributed to disability, they did not really follow through with their argument, especially when it came to the vignettes section of the interviews. As argued above, this conceptual dualism, in which what one actively believes does not correlate with what unconsciously does, has been noted in other studies such as that of Stalker *et al.* (1999). In the case of the present study, the social model is normally equated with normalisation. Even the informant who themselves has a disability viewed children with disabilities as being different from the 'norm'.

This perception manifested itself in various forms. The informant from the DREL, for example, clearly stated that children with disabilities were different from other children. This is primarily because physically children with disabilities have different visible characteristics. Other informants, such as the disability specialist in the ISS, mentioned that if someone had an impairment, but was able to lead an independent life, this would result in one not having a disability. However, when confronted with what independent meant, her perception of the word was a non-disabled one. This leads back to the observation that many people are not able to fully grasp the social model and fall back on a discourse of normalisation when called upon to expand upon their position or provide particular policy responses to disability. This was found throughout the interviews. It seems that informants have brought in their own experiences as a non-disabled person, and are unable to fully identify with the social model. Their perception of normality dominates their perception of disability and they only seem to have a non-disabled understanding of how things should be. For example, when the disability specialist from the ISS was asked to define what being non-disabled meant in practice, she mentioned how a person who has an impairment can go about his/her life without depending on anyone.

We need to look at disability from a different angle. Rather than focussing on what one cannot do or on the impairment as such, we could take an 'equality of opportunity' perspective. This perspective focuses on providing the right support in order that an individual has the same opportunities as their peers regardless of whether they have any kind of impairment or not. There was a tendency in the interviews to focus on the impairment. Although this thesis argues that it is important to consider impairment, it is not the centre factor leading to disability. Neither, though, are social issues alone of importance. They are both equally important since disability results from a complex interplay of impairment and social factors. Given the evolution of disability, it seemed that even with the new WHO classification (ICF), respondents were still clutching on to the structure and principles of the former classification. Within this particular case, not enough attention was given to tackling the social/environmental issues. Having an impairment does not entail one being disabled per se, since factors such as those highlighted by the disability movement, disability can also be the result of social, structural and environmental barriers. Furthermore, because one has a different or alternative way of doing things that does not mean that one is disabled. As discussed above, everyone needs support at one time of their life or another and usually this need for support does not lead one to be perceived as one being dependent or having a disability. Nor is this need for support perceived to be different from the norm.

Within the interviews, normalisation was the main issue that transpired, i.e. trying to make people with disabilities non-disabled. One could look into trying to support people with disabilities to become able to live their life their way, achieving the goals they want to achieve, rather than just trying to attain a fictional level of 'normality'. We need to redefine the very concept of normality. As previously stated by Shakespeare and Watson (2002) disability cannot be condensed into a singular identity: it is multiple and plural and we should embrace it as such.

In the case of children with disabilities, this category proved even more problematic than disability due to the ambiguities which surround the term children. The conception of being a child brought an even more oppressed dimension to disability.

Whether it was viewed as a life-stage or situational circumstance, children with disabilities (under the current legislation) are viewed as dependent or attached to a family unit. As touched upon by the informant of SA, it is impossible to think of the child without thinking of the family too and this was reflected throughout the interviews. It seemed that children are a non-entity; citizens by association rather than citizens in their own right. Furthermore, unlike non-disabled children (unless in higher education), certain types of legislation considered children with disabilities to be children until the age of 24. It seems that, if you have a disability, your childhood lasts longer. However, what transpired throughout the interviews is that children are also at a disadvantage. As indicated by the Children's Specialist from the ISS, the priority areas are those in vulnerable groups. Hence, if a child is not found in a situation of vulnerability, then they are most likely to be overlooked or not have an 'identity' within government policy. Children with disabilities, however, can often be identified as a vulnerable group or a group in need and, therefore, they have an identity within the policy context.

The vignettes too generated some interesting responses that fit in with the arguments set out here. In reviewing the accounts on an individual scale, it seems that João is not an independent entity. He and his mother seem to be a homogenous unit. The mother seemed to be at the centre of João's decisions, where any autonomy on his part did not transpire. Since, the mother was perceived as fully responsible for João, being the main decision-maker in his life, then she too encounters the same barriers that João does, disabling her on a more abstract scale. Finally, it seems that Joao, or any other child with disabilities, is not seen as an autonomous being, nor are they identified individually or as an individual. This, as illustrated above, may result in their needs and rights being overlooked in favour of the needs and rights of the person he is 'dependent' on.

9. Conclusion

This thesis sought to explore how key decision-makers within the Portuguese civil service formulate policies orientated at children with disabilities. In order to examine this process, it broke the question down into three main areas of focus: the decision-maker, existing policies and the concept children with disabilities. The decision-maker was analysed in the context her/his own professional identity. By adopting a combination of social identity theory (SIT) and identity theory (IT), this thesis explored professional identity as a combination of self-categorisation and role-identification: how one identifies oneself and what roles are associated with this identity. Through the use of a multi-method approach incorporating interviews and vignettes, this thesis managed to capture both the conscious and unconscious responses associated with this area. In addition, policy plans, international guidelines and legislation relating to children with disabilities that were highlighted within the interviews were analysed in order to build a clear account of the policy structure surrounding each of the interviewees, and the children with disabilities their policies are aimed at. This study also explored how children with disabilities were conceptualised, in order to comprehend at whom policies were directed and in what context. As a result of this study, various themes and approaches to children with disabilities emerged that illustrated the decision-making process and policy structure orientated children with disabilities in Portugal.

In the context of the decision-makers themselves, the interviewees tended to identify with those who are most like them or are closest to them. This was clearly depicted in the responses to the vignettes, where the majority of the respondents were women and identified with the needs of the mother. This identification could be construed in various ways, but two in particular seem to emerge. One interpretation could be that they are identifying with the category of mother, because most of the respondents are mothers themselves and, consequently, they identified with the needs of the mother as they were the most similar to their own. Another possible explanation for this is that the respondents were identifying with the underlying principles of the welfare state. Portugal, being a familialist welfare regime, by nature allocates most welfare

responsibilities to the household. As a result, this responsibility would fall on the head of the household, which, in the case of the vignette employed here, is the mother. For this reason, most welfare provisions would, by default, be directed at her.

Throughout the interviews, the respondents either identified with categories or roles when describing themselves and their opinions. This suggests that the combination of SIT (self-categorisation) and IT (role-identification) was an effective tool of analysis as it allowed this study to explore and identify these two approaches. However, there was a general tendency towards identifying roles when describing one's professional identity and approach. Senior level civil servants tended to identify with international guidelines, governmental manifestos and policy plans. They seemed to have a stronger identification with the government, and other senior level professionals, rather than mid-lower level civil servants in the same field. As suggested by Hogg and Terry (2000), self-categorisation can be aspirational. Drawing on Turner's (1975) work they state;

Social identity rests on inter-group social comparisons that seek to confirm or to establish in-group favouring evaluative distinctiveness between in-group and out-group, motivated by an underlying need for self-esteem. - (Hogg and Terry, 2000: 3)

The government is a very strong influence on the Directorate-Generals (D-Gs), especially their managing directors, who were the main interviewees from this tier. These entities have a normative function in formulating policy and implementing it. As a result, their 'in-group' is with the government, as they are their direct supervisors and viewed as a prestigious entity. If we take Hogg and Terry's (2000) analogy of people identifying and acting according to their in-group status, values and roles, the main intent of these civil servants is to fulfil the expectations of the government, or those of international organisations. These are set out in their guidelines, manifestos and policy plans.

However, these interviewees referred to themselves as individuals and not part of a collective group, when it came to their job. Perhaps because they have managerial roles, they do not identify with the employees within their own departments as an in-group but as an out-group. Only when contrasting their own area of competence with

other areas, do these informants have an in-group identification with their department or workgroup. These informants also tended to have more direct and idiosyncratic answers to the questions asked, especially with regard to the vignette. In schematic terms (see Carroll, 1993) this suggests that extended professional experience has led to their ability to provide such direct and concise responses. Through their experience they have built up strong schemas, and hence a consistent approach to tackling certain areas of policy.

In contrast, the lower-level civil servants interviewed in this study tended to refer to themselves as a collective or a departmental unit, perhaps because they have more collaborative rather than managerial roles. Nonetheless, departments such as the Institute for Social Security (ISS) and the Regional Directorate of Education in the Lisbon area (DREL) do have coordination/implementation roles. As reported by the informants for ISS, they have an intermediary and supportive role. These civil servants not only identified with legislation, but also the perceived need of the entities they work with and, to a certain extent, the public itself. These decision-makers are the direct and main recipients of their decisions and, hence, form part of the in-group these civil servants identify with in professional terms. These informants, in particular the disability specialist for the ISS, tended to provide less direct and less idiosyncratic answers to the questions posed. This could suggest that they have not had enough experience in the area investigated in order to form a strong schematic reference regarding their approach to this area.

Interestingly, the informant from the non-governmental organisation FENACERCI, too, identified legislation as a key influence on his professional decision-making. This is because, in order to secure state funding, his institution has to abide by state rules and guidelines, leaving little space for this institution to set its own independent goals. Although this is a 'private' cooperative, it is not entirely independent. The representative for Social Action (SA) has elaborated that although the state may not have the resources to offer certain services directly, it does however support the IPSSs that do offer these services. The state supports over 4000 IPSSs. The disability specialist for ISS also referred to the IPSSs as a form of obtaining provisions which

the State cannot offer. Essentially, these institutions act as an extension of the state. Since they rely on state funding they have to adapt to what the state requires. This was an issue raised by the informant for FENACERCI. This section of civil society is isomorphic with the state in the context of fulfilling the policy provisions intended by the state. Consequently, they form part of the same in-group as FENACERCI.

The informant for the Association for Disabled Persons (APD), on the other hand, views the state as an out-group. This organisation is completely independent from the state and campaigns for the rights and needs of people with disability. Hence it often finds itself in situations in which it opposes the policies or actions of the state. It is isomorphic with the state, in the sense that this institution campaigns for provisions that the state does not provide. However, this institution focuses mainly on issues relating to adults. Similarly, the majority of institutions that touch upon the needs of children with disabilities are usually oriented at the parents or family friends of children with disabilities, leaving a gap within civil society since there is no organisation that focuses solely on children with disabilities themselves.

In terms of the psychological schemas exhibited by the interviewees, there were certain schemas that manifested themselves more prominently than others. As discussed throughout this thesis the more experience one has in a particular area and the more often one repeats a certain task or process, the stronger the schema becomes which is attached to it (see Carroll 1993). This influence on schematic structures was particularly strong in two ways. One way in which these schemas were apparent was that there were a number of interviewees that kept referring to their past professions. A clear example of that were the respondents for FENACERCI and the DREL, who both described themselves as teachers, when in their current roles one was a Vice President of an NGO and the other a civil servant. In addition, they kept highlighting the fact that they had been 'lent' to their current employees (i.e. FENACERCI and DREL), suggesting either that they didn't really identify with the existing roles as strongly as they did with the teaching profession and/or that they didn't really belong where they were. As transpired through the interviews, this strong identification with a professional in-group may result in them identifying with the needs of those in this

in-group (i.e. teachers) rather than with children with disabilities. This was especially true in the case of the civil servant in question from the DREL. The informant for the National Secretariat for the Rehabilitation and Integration of People with Disabilities (SNRIPD) also had a detached approach to her job in the secretariat. This is partly because she had previously worked for many years in the voluntary sector and had only recently taken up this post. In addition, her department did not have a sound positioning in the structure of the civil service, with this unit changing ministry, hierarchy and function as a result of changes in government. As a result, it is perhaps not surprising that this civil servant was unclear about where to position herself within the annals of government, as she was still finding her footing as was her department. Interestingly, she seemed to identify more with policies within education, and particularly special needs education, as a policy area rather than social security, which was the ministry in which she was located. This was because she dealt with issues within the field of education, and was more interested in them than the other areas she was required to engage with as part of her remit within the field social security. Hence, she identified more with a particular policy area (education policy), rather than the ministry in which she was employed. This response was quite unique amongst the informants questioned as most other mid-level civil servants did not seem to enjoy the autonomy to focus on particular areas of concern or interest to them, nor did they attempt to develop such freedom to specialise in certain areas.

Another strong manifestation of these schematic structures was predominantly found in the interview with the informant for Regimes (R). When asked how she would define children with disabilities, she kept referring to legislation. When asked what she personally thought, she said that her thoughts were not important or relevant in this context. Professionally it is what the guidelines say that is of importance, not her personal opinion of this legislation. She works in the Department of Regimes, and has done so for a long time. As a result, the decision-making processes in the department seem to have been ingrained into her professional conduct. This is perhaps unsurprising given that this department deals with the rules and guidelines used to allocate particular benefits. This department concerns itself with the administrative categories discussed by Fulcher (1989) and Bolderson and Mabbett

(1991), where one receives certain benefits by virtue of belonging to a specific category. The remaining interviewees were not as clear cut regarding their professional role. However, most interviewees (to a certain extent at least) highlighted how their conduct and decision-making power was restricted by set rules, guidelines, criteria or demands.

One of the most influential international documents at the time of the interviews was the International Classification of Functioning (ICF) produced by the WHO. It had just been published in Portuguese and was in the process of being disseminated. However, although this classification tried to encompass the environmental barriers faced by person with disabilities, as discussed by Barnes (2003), it still maintains the previous three-fold system of the 1980s WHO model. Since, the ICF does not highlight effective measures to monitor and tackle environmental issues concerning disability it is hard to do so, especially for those who have no prior experience or understanding of this approach. This point was noted within the interviews.

Most of the informants identified impairment as the main source of disability. As suggested by Barnes (2003) countries such as Portugal have difficulties in grasping the social model of disability, due to limitations in language as well as financial means necessary to sustain this approach. By the ICF failing to address these issues, it can result in countries also failing to address those issues themselves as they may not know how to achieve this. In addition, the other international organisations and guidelines mentioned within the interviews were just as limited or limiting as the ICF. The Standard Rules for the Equalisation of Opportunities of Persons with Disabilities pushes for integration and not inclusion in schools which, as suggested by Save the Children (2002), pushes for a more individualised approach to disability, where the emphasis is on 'normalising' the individual child. UNESCO, on the other hand, still adopts outdated terminology such as 'handicap' that may elicit a seemingly outdated perception of disability. However, as has been suggested by Allan (2006), the concept of inclusion too needs to be readdressed and re-conceptualised, as it is not currently serving its purpose.

Rehabilitation, which is heavily emphasised in the ICF, was the main form of support advocated within policy plans and legislation. It is the basis of most policy measures for persons with disability, especially those regarding children. The majority of provisions orientated at children are in the form of specialised support tailored to their particular disability. Whether it be Early Childhood Intervention (ECI) or Special Education, the focus is on rehabilitating the disability. In addition, in a social context, integration has been the main measure advocated within policy towards disabled children. Integration, as discussed in Chapter 4, is advocated by the Standard Rules in the context of education. Within Portuguese policy plans and legislation, integration has been advocated with respect to mainstream schools, in the work force and society in general. It has been discussed and emphasised significantly more than inclusion, with regard to disability. Both integration and rehabilitation are approaches that suggest a 'normalisation' approach to disability. They are orientated at adapting persons with disabilities to a social 'norm', rather than adapting society to the needs of the disabled person and making all aspects of social life accessible and inclusive for person with disabilities. Normalisation is a substantive area in the disability related literature, and rightfully so. Within this study all interviewees highlighted disability in the context of normality or a perceived 'norm'. Although key texts on disability refer to this perception of normality as oppressive, human beings have a tendency to develop a perception of normality and to compare and contrast individuals to this preconceived notion of what is normal. Titchkosky (2000) highlighted that every individual is unique and has a unique set of beliefs, attitudes and understandings of what normality is. Given that all the interviewees, with the exception of one, do not themselves have disabilities, they do not share experiences with people with disabilities. Consequently, they experience and understand life and normality from a non-disabled perspective. The interviewee with disabilities also noted the concept of normality, but from the perspective of an outsider or someone who is different to this perceived norm. Nonetheless, this informant wanted to achieve normality by having independent living.

Armer (2004), in his search for a social model of disability, discussed the discourse of normality. Within this, he highlighted Oliver's (1994) argument that the logic of

modern western capitalism has established a deeply embedded conception of the autonomous worker. Echoing Stone (1984), Armer argues moreover that being 'normal' entails membership of a certain group within society, which is deemed to represent this version of normality. Within western capitalist society, the definition of normality is closely associated with fulfilling the role of the autonomous worker, and therefore, membership of this group usually excludes people with disabilities and, to a certain extent, children too, as they do not work, pay taxes or live independently. As illustrated by the interviews this conception is the preset schema that the interviewees associated with normality. This normalisation approach is not particular to the participants in this study. This approach filters through from international guidelines to national legislation and to the individual citizen.

It is virtually impossible to meet the needs of the children with disabilities without some form of categorisation. Bolderson and Mabbett (2002) illustrated this point by stating that the social model suggests a shift in the distribution of provisions, from a needs-based approach to rights-based approach. They suggested three different measures in order to tackle this shift, which are as follows:

1. The abolition of separate 'incapacity' benefits: all people who are unemployed or unable to work will be eligible for the same unemployment benefit or job-seekers allowance.
2. The replacement of disability benefits based on loss of function and inability to perform tasks with payments made as compensation for loss or damage arising vicariously from social structures and barriers.
3. The abolition of the term disability and promotion of universal access to all services and activities in society. - (Bolderson and Mabbett, 2002 : 3)

Although these authors did not adopt a children's perspective, the scenarios above depict ways in which one can remove the term disability from policy. Although, theoretically, it would possible to abolish incapacity benefits and replace them with unemployment benefits or a job-seekers allowance, it still remains the case that some disabilities incur higher living costs than others and require, therefore, additional financial support for these costs, especially if the individual concerned is not

employed. As a result, other provisions would be needed such as a Disability Living Allowance or such like, which would still require at least some focus on the specific disability of each individual. Furthermore, in applying the social model to this scenario it might be interpreted that having a lack of skills should be viewed as a disability and be given equal importance as other forms of impairment. As discussed in Chapter 8, children within Portugal are not usually mentioned within policy except as dependents. In these cases, their family is entitled to family allowances. However, certain allowances do need to take into account the child's impairment and needs.

In terms of the second measure, it is hard not to take an individualised approach given that there are still extensive barriers to disabled persons' participation within society that are still yet to be recognised. In order to identify and tackle these barriers, one must inevitably recognise the disability or impairment first, especially when there are barriers that are specific to that impairment. Early Childhood Intervention (ECI) is a key area in policies regarding children with disabilities within Portugal. Although this is a 'whole family approach', in order to provide the specialist support that the child needs their impairment and disability needs to be taken into consideration.

The third and final measure also has to take an individualised approach in order to identify where the disabling barriers are. Cost aside, there are various implications to such an approach which are not at all straightforward. For example, certain needs or barriers associated with certain impairments (perhaps those less prevalent or more complex) may be overlooked due to this abolition. Furthermore, discrimination has proven hard to tackle when it comes to disability; although words and meanings may change, the underlying views often still remain. As Social Identity Theory (SIT) contends, one's expectations and beliefs will always be used to judge and stigmatise others, (Stets and Burke, 2000). The repercussions of this resonate throughout this thesis.

As Bolderson and Mabbett (2002) suggest, there are significant shortcomings in taking the social model of disability and applying it to social policy, especially if one views disabled as a homogenous group:

The debate over disability is marked by a deep-rooted ambivalence in our attitudes to identity and anonymity. We ask, on the one hand, to be recognised and validated as individuals, yet, on the other, we value our privacy and are drawn towards policies which are consistent with anonymity. It is not possible to devise an approach which reconciles these irreconcilable ideals.
- (Bolderson and Mabbett, 2002:13)

The above approach requires disabled persons to be seen as equal, not only in terms of opportunities, but also in terms of how one is perceived. This is virtually impossible, if only at present, as there are certain barriers that need to be eliminated in order to achieve this, and these barriers require some recognition of impairment. This is not to say that with changes in society, technology, research and development these issues won't become obsolete. However, these are the barriers that need to be tackled at present.

There are two principle conceptual models of disability: the medical/individual model and the social model of disability. However, what the recent literature seems to suggest is that we should not think of disability exclusively in medical/individual terms, nor in the exclusively social terms. Rather, what is needed is a comprehensive middle way between these two approaches that fully grasps and addresses the conditions inherent to disability. As Allan (2006) argues, we need to reinscribe ourselves as actors, and re-conceptualise ourselves as beings, in order to build a fully inclusive society. Conversely, one also needs to understand the audience whose perceptions need to be challenged, and understand how one should raise-awareness on these issues in order to tackle them more effectively. As Gronvik (2007) illustrated in his analysis of five seminal texts in the field of disability studies, this literature is filled with 'fuzzy buzz words' that result in inconsistencies, incoherencies and uncertainties, as well as conflicting arguments about the meaning of words and concepts, that get in the way of developing a comprehensive theoretical

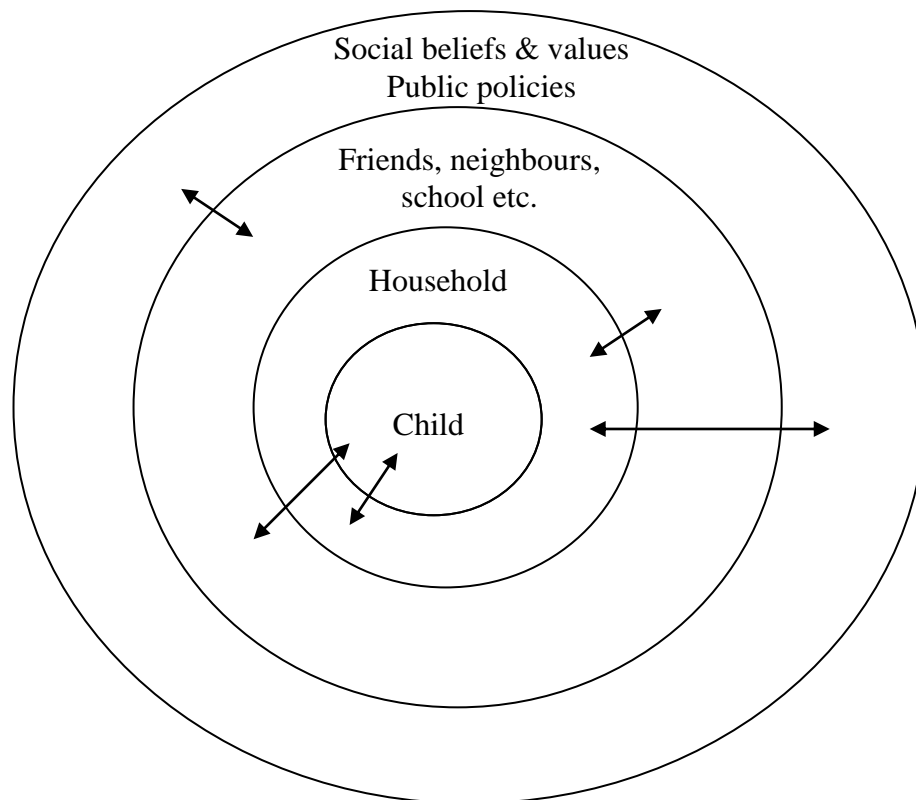
framework on disability. Low (2006) also noted this disparity and suggested an alternative model or conceptual framework for disability:

- 1) A philosophy which recognises that disabled people are both radically the same as non-disabled people in terms of their common humanity, and at the same time radically different in terms of their need for support
- 2) A model of society that espouses a concept for equality which accords a central place to the need for society to provide assistance to enable disabled people to realise that equality and make their maximum contribution to society
- 3) A conception of inclusion which acknowledges the inherent nature of necessary support
- 4) A conception of inclusion that acknowledges the importance of special support, provided it is of an inclusive character
- 5) A pragmatic approach which recognises that inclusion entails modification of the impairment through prevention and cure, and modification of the individual through treatment, training and rehabilitation, as well as modification of environment
- 6) Recognition that inclusion is a two-way street which requires the disabled person to come halfway to meet society and at the same time as requiring society to make its maximum possible accommodation to him. – (Low, 2006: 111)

What Low attempts here is to call for a model that incorporates necessary elements of the medical model within the social model, constructing an approach similar to that advocated by Crow (1996). To a certain extent he seems to be advocating something similar to the model of disability set out in the ICF, but with some additional ‘social’ elements. He advocates the need to for us acknowledge and understand impairment, but also the social barriers presented to people with disabilities. He also identifies the need to fully address the concept of equality and what it entails, and tries to tackle the shortcomings of the current conception of inclusion. However, the fifth point of his argument places more stress on medicalising disability and correcting it rather than on the environmental issues, an approach which can be quite limiting. Low’s model also still hints at a normalisation based approach to disability. In the social arena, what is needed is a redefinition of the perception self and the self in the social context, and, in turn, the other. Rather than drawing upon distinctions between disabled and non-disabled actors, perhaps one should focus on the commonalities between them and how needs can be met on

those grounds. For this, one needs to redefine and re-conceptualise our understanding of key terms such as support, inclusion and equality.

In addition, the interview and documentary data analysed reflected on the notion of dependency. The concept of dependency, as stated in the existing legislation, is age specific, but is mainly defined by disability and education. If someone has a disability then they are viewed as dependent until the age of 24 and are entitled to benefits on that basis. In the case of non-disabled persons, an individual is only considered as a dependent until the age of 24 if they remain in education. If they do not remain in education up to this age they cease to be a dependent at the age of 16. Hence, between the ages of 16 and 24 dependency is defined by whether the person is within education. Although disability is one of the key factors for defining whether one is considered to be a dependent after the age of 16, before that age everyone is considered as dependent regardless if they have a disability or not. As illustrated below, children are not addressed directly by public policy unless they are considered to be at risk in some way. Most social structures and policies are instead constructed around the family, services and institutions that work directly with children.



- (adapted from Hill and Tisdall, 1997: 4)

As highlighted within the latter chapters of this thesis, children are usually referred to only as the children or descendents of citizens, indicating they are citizens once removed, or citizens by association, but not themselves full citizens. Consequently, children cannot fully enjoy the social rights ensured by citizen status. The problem with viewing the welfare state from a welfare-capitalist perspective, as hinted by Armer (2004) is that it glosses over the non-working (not unemployed) segment of the population. It views the welfare state from the perspective of the working man, where this relationship with the state is more clearly defined. Children's relationship with policy and the state is more complex and multi-faceted and not as clear cut as that of working citizens.

Viewing children as dependents, results in policy provisions being aimed and directed at parents rather than the children themselves. This might result in policies

which support the parents and network of services caring for the welfare of their children and not children's welfare per se. This was especially noticeable in the context of Social Action, where the state merely supports IPSS to provide services in this area. Within the field of education, this seemed to be the case too (see Chapters 4 and 5). Measures like childcare are viewed as a means of allowing parents to work and pay taxes, as are family allowances and child benefits. This was a common view throughout the interviews. If this is the case, then children live in a welfare state micro-sphere: a welfare state run by parents or primary carers. Consequently, children can potentially be living in any of the welfare regime clusters, depending on parenting styles and the resources available to their primary carers.

In the context of children with disabilities, children's social networks are structured in a similar fashion to that illustrated in Hill and Tisdall (1997). Between the ages of 0-6, Early Childhood Intervention presents a network of support to children with disabilities and their families. Although this provision is mainly directed at supporting and educating parents in caring for their child and their disability, it does focus on the child's needs. However, this provision is only available to children aged between 0 and 6 years of age. However, children with disabilities benefit from specialised support within schools and, depending on their disability, are entitled to particular aids and support out with the school setting.

From the age of 6 until one becomes a 'young person' (an age that is yet to be clearly defined), the approach to children with disabilities is similar to that of other children. The only direct mention of children with disabilities is within policies aimed at children who are considered to be at risk or in disability related policy which apply to adults too. As mentioned above, children with disabilities do have specialised support within schools. Children with disabilities probably also have more interaction with civil society than other children, since most measures of social support and assistance, as well as certain special schools, are provided by the IPSS. This coverage though is not universal. Waiting lists are long and benefits are modest and limited. Although these are difficulties confronted by parents, the children are the ones who mainly suffer. This is a phenomenon highlighted by Sousa Santos

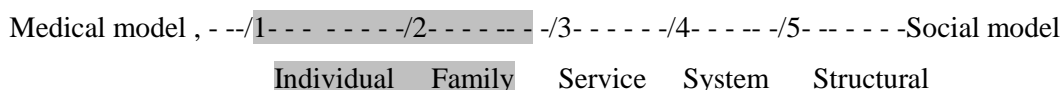
(1994) in his illustration of the state/civil society divide. Although in theory where the state coverage stops, civil society begins, civil society is particularistic and, as a result, does not cover all those areas that the state fails to provide for. Rather civil society tends to provide for those areas with largest and best organised interest groups.

In certain contexts, children are also viewed as the future workforce. As highlighted in Chapters 5 and 6, there have been initiatives aimed at facilitating the integration of young people and particularly young people with disabilities into the work force and the political arena. Initiatives such as the Portuguese Youth Institute (IPJ), promote an array of youth work initiatives to support the young population in developing their skills and becoming more politically engaged. They are usually carried out in partnership with the civil society and are accessible to all. Within policy plans and legislation young people were widely discussed and did not have labels such as dependent or descendent of citizens attached to them. They are listed as citizens in their own right. When children with disabilities become young people with disabilities, they too are mentioned directly within Portuguese policy. In recent years there has been an investment in developing measures to support the transition into work for young people with disabilities. A few interviewees mentioned the transition into work. They said that due to the lack of funds to support people with disabilities, the state had no choice but to develop measures to integrate people with disabilities into the labour market and has, according to them, become quite successful in so doing.

These approaches to integrating people with disabilities into the labour market feedback to the notion of normality associated with social membership, and how all should aspire to membership of this group. Young people are classified in policies as those at the start of their working life, or those making that transition. Hence, they are gaining membership of the 'normal' social group and, as a result, are considered as citizens. They are also reaching the age at which they can vote. It is worth considering whether, if children had voting power, they would be treated differently in policy. Furthermore, it is worth noting that although countries such as Portugal

have ensured measures to prevent child labour, they have not taken precautions to provide children with equal status with adults.

In addition to the interview and documentary data, this thesis also explored the civil servants' decision-making through the use of vignettes. This technique allowed this study to explore unconscious attitudes and beliefs on issues regarding policies orientated at children with disabilities. As a result, it opted to present a true story, to see how these decision-makers identified with this story, what they identified as being the issues that needed addressing, and what solutions they presented to these issues. As illustrated above, the majority of the interviewees identified with the single-mother in the story and identified her needs as that which needed to be addressed. Hence, not only did they identify impairment as the main cause of disability, but they also identified the lack of means the mother had for caring for her child as being the principle problem. Disability, in terms of Sim *et al.*'s (1998) locus of control, lay at a self-familial level (highlighted below), where it refers to the externalisation of problems to the relationship held by the individual with the family and/or guardians.



Enhanced Locus of Control Model – (adapted from Sim *et al.*, 1998: 60)

Nonetheless, there were some suggestions that extended to other levels. There was a general consensus between respondents that certain services were the responsibility of other departments and/or ministries. The respondents within the ISS agreed that schools should be the 'motor of support' (ISS – children specialist). Schools could be the centre of social networks and extracurricular activities which aid and support parents in caring for their child. On a more global scale, this suggestion is similar to that of the representative for SA. They place the responsibility of running residential homes for respite care in the hands of Education. If we look at the response from the

informant from the DREL, she claimed to have been a teacher and, as a result of this, she recommends an informal support network. When this respondent worked as a teacher she made recommendations to parents about caring for their children and helped them work towards constructing a support network, which would assist them in this. Social networks are a common phenomenon within Portugal. Wall *et al.* (2001) explored social networks in Portugal and found that, regardless of education and social status, people usually relied on their families for childcare support, especially their parents. As a result, such a suggestion is not that unreasonable as it seems to be the cultural norm. Although this response is similar and hence correlates with the notions of the respondents from the ISS, it lacks one component. Although the respondents from the ISS were hinting that the school should help more to support parents, the respondent from the DREL was more concerned with helping parents to help themselves.

On a 'micro' (services) level the vignettes generated varying responses. However, education was central to debates in terms of the 'micro' sphere (see Chapters 5 and 6). The representatives for SA, Regimes and SNE all discussed the ideal of having inclusive mainstream schools. The representative for the SNE elaborated that there are spaces available in mainstream schools that are not made use of. The respondent for SA, on the other hand, argued that the term inclusion does not accurately describe the reality faced by many children with disabilities, and that the term 'integration' is more appropriate. The respondent for Regimes felt, however, that there are increasingly fewer special schools due to the fact that more children are attending mainstream schools with integrated special support. It was only the top level policymakers that elaborated on inclusive schooling. However, as discussed above 'integration' is the main word used within legislation and policy guidelines, which suggests that for those who rely heavily on legislation, there is no reason for them to be acquainted with and to implement an inclusive approach.

The representative for SNE, like the informant of IR, felt there was a need for a system that compiles information on and alerts citizens to the provisions, support and benefits that they are entitled to. Interestingly, the respondent for SA highlighted that

the ISS and certain IPSSs are equipped to provide these answers. This, however, does not seem to be the case in the ISS. Although the ISS specialist for disability referred to the IPSSs, as previously stated it seems that both the specialists for disability and the specialist for children believe that education should play a more substantial role in providing answers to these problems. Perhaps the state would benefit from further IPSS partnerships directly linked with education. However, the private-public partnerships have been subject to criticism. Although there has been investment in the private sector in Portugal, there is a 'lack of systematic evaluation of the performance' (OECD, 2003: 78) of public-private partnerships, especially about where they could be operating more optimally. This systematic evaluation could also highlight areas that need further attention or investment.

The shortcomings of the state elucidated by the vignette responses and interviews seem to correlate with the criticisms by the OECD of Portuguese welfare state. Portugal is a moderately industrialised state and, as touched upon in Chapter 2, that has reached a certain level of political centralisation and organisation (Ramalho Correia *et al.* 1997). As stated by Ramalho Correia *et al.* (1997: 227): 'economic performance has never allowed the creation of a real Welfare State, unlike most of the industrialised countries'. Portugal, in the period preceding the interviews, had the second lowest GDP per capita in the EU and, although its economy has grown significantly in the past 20 years, there remains a substantial gap between the Portuguese income levels when compared with other EU countries (OECD, 2003).

From a 'macro' or structural perspective, one of the main concerns is financial sustainability of the welfare system. Both the representatives for Regimes and from the SNRIPD mentioned concerns with costs and sustainability of offering additional provisions to the child or family in the vignette scenario. The respondent from the SNRIPD, in particular, suggested that policy changes which could be introduced without incurring costs would be ideal, and she placed emphasis on preventative policies (e.g. those which could decrease the number of children born with disabilities). These financial concerns highlight the economic concerns of the state. The weakness of the economy, especially compared to other European states, and an

unsustainable welfare economy make changes to provisions, or personalised state provisions virtually impossible. An innovative approach to tackle the issue of the limited of provisions has been highlighted by the respondent from the DREL. The government, she reported, has been pushing for an extension of school hours in order for parents to be able to stay longer at work. In fact, provisions of this nature are in the best interest of the State as it increases productivity and hence can be more cost effective.

The remaining respondents were more concerned with the structural issues which emerged out of the vignette. Whilst the representative for Regimes highlighted that her department did not offer the personalized approach that SA did, the SA representative highlighted that the state has practically no institution that provides in the form of social support or action. This notion ties in with Portugal's (1996) elaboration on the devolution of governmental competences to civil society, resulting in the de-institutionalisation of the state. However, although the state may have partnerships with private institutions that provide support services, if these institutions are not being systematically evaluated, then this personalized approach will be nullified. Poor lines of communication are evident within the state bureaucracy, as reflected by the incoherence between the responses of the DGSS and the ISS, which are part of the same ministry.

From these observations it seems that disablement or disability does not only lie at individual level. It lies at individual-familial level, because children with disabilities are not seen as independent beings. It lies at familial-micro level (services orientated at the family) because of the responsibility that families have to care for their members and the lack of services and support available to them. It lies at macro-micro level due to the ineffective dissemination of information about the services which are available and the lack of an umbrella organisation that lists the rights and benefits that individuals are entitled to. Disability permeates all levels of the policy making and implementation because of the limited conception of disability that is pre-eminent in the policy process.

In sum, this thesis sought to explore how key decision-makers in the Portuguese civil service formulate decisions regarding policies orientated at children with disabilities. It found that professional identity played an important role in decision-making. By combining the two pivotal theories of identity, SIT and IT, this thesis found that professional identity is not only made of job titles or descriptions. Professional identities are formed from a combination of perceived categories and personae, as well as associated roles. In terms of self-categorisation the participants in this study identified with certain groups and categories over others, highlighting a dualism between in-groups and out-groups in decision-making, which varied with context (see Hogg and Terry, 2000). The decision-makers tended to formulate their decisions in the context of their membership of a particular social group and tended also to orientate policy solutions at this 'in-group'. For example, certain interviewees identified with the teaching profession. As a result, they tended to view issues and support structures in the context of the teachers and not necessarily the child. Similarly, in the vignette, the majority of interviewees identified with the mother and sought ways to support her, rather than the child themselves. In terms of role identification, this study found that professional identity also incorporates rules and guidelines associated with ones job. This is clearly depicted by the tendency of senior level civil servants to identify with policy plans and international guidelines, whereas mid-level civil servants and those from the IPSS tended to identify more with legislation, as these documents play a key role in their respective jobs. As a result, this reaffirms that the basis for decision-making regarding children with disabilities is how the term 'children with disabilities' is identified and conceptualised by the decision-maker, and what the identified rules and guidelines associated with this topic are.

The term children with disabilities was conceptualised in various ways. Some interviewees defined children with disabilities as children who had an additional characteristic(s), attempting to adopt a more inclusive and politically correct approach. However, all participants at some point in the interview referred to them as children with disabilities or who have disabilities, and also as dependents. According to legislation children with disabilities remain so until 24 years of age and

so they are considered to have an extended childhood. In that period they are viewed as the descendents and dependents of citizens (a status similar to that of children) and, hence, not citizens themselves. This results in Stone's (1984) describes as second-class citizenship. After this period, if this person with disabilities does not have a job, and is living on disability allowance, they are viewed still viewed as dependents. It is important to note that citizenship status is linked to dependency and employment, rather than disability as such.

The vignettes introduced us to the notion of the disabled family. Given the structure of the Portuguese familialist state, most welfare responsibility lies on the household and, as a result, the responsibility for caring for and supporting the person with disabilities is of the family. Studies such as Reichman *et al.* (2008) suggest that the responsibility for caring for a child with disabilities can be considerably stressful, costly and limiting to ones life, and so places certain limitations on the family as a whole. This experience can be disabling in itself, as the family encounters the similar disabling barriers as the child. Reichman *et al.* have noted that this is an area that is yet to be developed in the existing literature of disability and one which needs addressing. In the case of this thesis, most of the policy suggestions and provisions highlighted in this thesis were orientated at the family and supporting the family rather than the child, underlining that fact that this is a very important area for additional research. The child is rarely seen as an individual, except in extreme situations such as being risk or when they are ready to enter the labour market. This transitional age is when a child becomes a 'young person.' The familailist welfare structure puts into question the ability and effectiveness of implementing policy measures, especially in the field of children's rights. Consequently, it is an approach must be challenged.

Like Stalker *et al.* (1999), this study also found that, although decision-makers wanted to take an up-to-date and contemporary approach to disability, there was a tendency to adopt a 'normalisation' based approach to disability. There are various reasons that account for this approach. Firstly, the two main approaches to disability in Portugal are rehabilitation and integration. As has been discussed in this thesis,

both these approaches suggest a normalisation approach to disability. However, as has been observed, these approaches are not that dissimilar to approaches advocated by international organisations and guidelines such as the WHO, the Standard Rules and UNESCO. The ICF in particular was discussed extensively throughout the interviews. Although these guidelines try to adopt a more social model based approach to disability, as Barnes (2003) has suggested, they do not offer any effective implementation and monitoring tools. For a country such as Portugal that has a limited vocabulary associated with disability, and hence a limited means of expressing the different ways in which disability can potentially be understood, there needs to be a more comprehensive and effective tool for addressing these issues. Nonetheless, at the time of the interviews, the ICF was in its early stages of dissemination. It would be interesting to have a follow-up study to view how this implementation has progressed, whether perceptions and approaches to disability have changed as a result of its introduction.

As suggested above in the social-psychological literature on mental schemas, people tend to interpret information in the context of their previous experience. Someone who does not have the experience of having a disability may not be able to fully grasp or comprehend what the social model asks. In analysing the interview data, it seemed that there was a push for equality. However, equality was equated with 'sameness', which could be linked to the 'normalisation' approach discussed above. Perhaps it is not only the term 'disability' that needs to be challenged, but also people's perception of certain terms such as equality and even participation and inclusion. This could be a possible avenue for further research.

In sum, there were various implications identified within this thesis, for policy and practice. If one is to look at the literature (see Borzel, 2000) Southern European Welfare Regimes are often criticised for bad compliance of international and EU guidelines. These observations have been particularly dominant in the environmental policy arena, where this 'bad compliance' is often referred to the 'Mediterranean Syndrome' (Borzel, 2000). However, this 'bad compliance', as suggested by Borzel (2000) in the context of environmental policy, is also the result of a variety of factors

that vary from state to state in the Mediterranean region. In the case of Portugal, this thesis found that this limitation lay not only in the state and society, but also at international level.

It seems that European and/or International organisations do not do enough to address the implementation of their guidelines. Although these organisations have highlighted and defined the problem areas and what needs to be addressed, they do not go into enough depth about how to address them. For countries that are not well acquainted with these problems and issues and have no conceptual basis and grounding on these issues, addressing them can be challenging. This is because policy structures are being built on patchy or rocky foundations. Perhaps these International and European instruments should provide more pluralist support and guidelines as to how to address the issues they highlight, especially for countries who do not have the intellectual and physical foundations to build them on. In addition, there needs to be a common conception, understanding and approach to policies oriented at children with disabilities throughout these organisations, as some can contradict each other rather than support each other. Perhaps with the new UNCPRD there will be a committee that can address these issues effectively and their implementation. In addition, there could also be a European body that too addresses and provides support on these issues.

What the interviews told us is that there is too much flexibility and not enough training and/or consistent guidelines or guidance regarding the areas these policy actors are making decisions on. In this case it was children with disabilities. The informant for SNRIPD tended to push for the needs she had identified as a worker in the voluntary sector. The informant for DREL tended to identify the needs which she had identified as a teacher. The more senior level civil servants tended to either identify with governmental approaches and/or the approaches they are accustomed to. There was no clear approach to this policy area or clear common goal. In addition there didn't seem to be much knowledge of other departments, where each entity was more concerned with their department's agenda. This tells us that there are limitations in the coordination of common policy objectives not only within specific

departments but across ministerial areas and the civil service. The interviews highlighted that there was a lack of consistent communication and partnership between departments not only hierarchically but also laterally. This resulted in an incoherent system or policy structure.

This shortcoming is clearly an area that needs to be addressed. The informant for International Relations suggested the development of an ‘Umbrella Organisation’. She stated that there was a desperate need for an organisation whose main function was to adopt, monitor and articulate the implementation of certain policy goals, especially those expressed within the international arena. By having an umbrella organisation that articulates and coordinates the implementation of policies such as those regarding children with disabilities, and informs and trains policy actors on these issues and this area, allows policy decisions to be well-informed and more uniform and consistent, where all policy actors will be working towards a common goal and/or objective. In addition this coordinating body, in monitoring all departments and being aware of what their role and function, would also be able to facilitate and monitor their partnership and communication in achieving common policy objectives. This organisation would also be a specialist on ‘children with disabilities’ and not on policies regarding them, which is the case of civil servants. This could result in a more coherent policy process.

In terms of representations of ‘children with disabilities’ in policy, it seemed that children with disabilities were seen as part of a family unit and rarely as an individual. Policies are oriented at families with disabilities, rather than just children with disabilities. In addition, disability was generally defined in terms of impairment. If one has an impairment, then they have a disability and are entitled to benefits which are mainly in the form of cash benefits or rehabilitation. With the exception of certain areas of labour activation and to a certain extent schooling, there were very limited policies aimed at tackling the social and/or structural barriers encountered by people with disabilities. However, it is important to note that Portugal is a relatively new democratic state. It is yet to witness a strong social movement within this area, such as in the UK. As illustrated in this thesis, disability is constructed differently

within Portugal from that of the perceptions documented in British academic literature. As a result, there is a tendency to rely on International/European guidelines and to try to meet particular benchmarks, such as rehabilitation, education and so forth, without grasping the more general understanding of disability these measures are trying to portray. Without this general understanding, policies will be mismatched and incoherent and there will be significant cleavages between them, which will limit the construction of an inclusive society. These cleavages become even more apparent and significant in countries such as Portugal where there is limited communication and coordination of policies between state departments. In addition, as seen in this study, all the interviewees in the civil service were women, and all of them tended to identify with the family as the beneficiaries of policy measures and whom policy was oriented at. This shows that policies and international guidelines can be engulfed into this familialist regime, where the child is the responsibility and concern of the family, which limits any inclusive measures that may be suggested. Measures need to be developed in order to penetrate this system in order to produce the desired outcome of policy, rather than just incorporating policies into legislation and letting them take their course.

With an umbrella organisation, one can address these issues. As elaborated above, such an organisation could follow through the implementation and execution of policy and by focussing on the desired outcome, could help achieve it. However, this organisation could also address the societal implications of disability and the social construction of ‘children with disabilities.’ The understanding and construction ‘children with disabilities’ with society, could be tackled through education and training, as well as through raising awareness.

Socially and culturally people with disabilities in Portugal, whether children or adults, are usually viewed with pity rather than injustice. As a result, people with disabilities are pitied for having an impairment and having to manage it, rather than being an oppressed minority conditioned by the social and structural barriers surrounding him/her. Since disability is not just a state issue but a social issue, this societal perception also needs to be addressed. In addition, organisations such as

FENACERCI raise funds by playing on this sense of pity, and enticing the public to donate money to help these ‘poor’ children. Perhaps they should invest on raising awareness on the social barriers children with disabilities encounter and how to build a more inclusive society.

In the past, Portugal has successfully raised awareness on a number of issues through the use of the media. In the equality arena, the State had a very successful TV ad addressing the issue of equality in the household and the division of labour and household chores between men and women and raising awareness to equality (Ministry of Education, 1999). Equally, perhaps the State could invest on addressing disability and challenging its perception. A possibility could be to look at the Portuguese language and the terminologies it adopts regarding disability and make it more inclusive and less derogatory. Re-defining disability and the term disability (deficient) would aid the process of re-conceptualising and re-identifying what disability is and what it means in a wider context. This would then allow or ease the process re-conceptualising inclusion and what it means and what it entails, as well as, equality, accessibility, non-discrimination, participation and other fuzzy buzz words of great importance to addressing disability and tackling disablement.

This study did encounter certain difficulties. The main drawback was the number of participants involved. Initially I intended on interviewing one ‘specialist’ in every department, within each of the selected Directorates/Secretariats. However, when I asked for permission to interview these informants I was only allocated the interviewees who participated in my study. These informants were part of one particular department, within each Directorate/Secretariat, that was deemed to work with policies regarding children with disabilities, and these informants were the labelled as the ‘specialists’ on children with disabilities. When I tried asking each individual department within each Directorate/Secretariat for an interview on policies regarding children with disabilities, I was always referred back to the informants that took part in this study. Although I have flagged up this issue as a drawback, this process was quite informative in itself. It showed that there are not that many specialists and that the existing specialists were not specialised, nor trained, in the

area of disability nor children, but rather on the policies regarding these demographics. As a result, they were not experts on the issues they are making decisions on.

Nonetheless, having a small sample also allowed me to engage with the data and produce a qualitatively rich study. I was able to explore each 'policy decision-maker' in detail, as well as her/his approach to decision-making, which has made this a unique study. Having a small sample gave me the space to explore more extenuating factors that can influence decision-making and the people making those decisions, and the relationship and interaction between the two. Having a larger sample would limit my ability to bring out as much from the data.

One of the other difficulties I encountered was justifying the amalgamation of social psychological/sociological theories to analyse my data, rather than more conventional approaches. However, having chosen these theories after conducting the interviews, it was clear they were the best approach to analyse the data. The interviewees spoke in categories and roles. I am this and I do this, and this is my role and this defines what I do. SIT and IT allowed me to look at perceived social and normative structures surrounding the individual and also their associated identity through their perceived roles and self-categorisation. As a result of that I was also able to view how they identified and engaged with others. This process again allowed me to bring out the best in my data.

All-in-all the experience of doing this thesis has been a fruitful and enriching one. It showed that a limited number of interviewees is not limiting, provided the interviews are detailed enough and one has a strong enough theory to analyse them and bring out the most in their content, and that most things can be possible if you have a strong research design and structure to back it up.

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I. Appendix

Letter requesting interview in Portuguese

Excelência,

O meu nome é Sandra Sibel Cabrita Gulyurtlu. Após de ter feito um Mestrado na área das políticas e direitos da criança, onde a minha tese se intitulou, ‘O retórico Convenção dos Direitos da Criança da ONU para os direitos de criança com deficiências,’ actualmente estou a fazer um doutoramento na Universidade de Edimburgo na área de política social, supervisionado pela Dra. Kay Tisdall, (especializada nas políticas sociais de crianças, nomeadamente crianças com deficiências, onde actualmente está envolvida num projecto Europeu designado a investigar a estrutura de diferentes estados da UE em termos de crianças deficientes) e o Dr. Ian Dey, (Director do departamento de políticas sociais da Universidade de Edimburgo). A minha tese intitula-se ‘A estrutura das políticas sociais para as crianças deficientes no Governo Português’. Tendo trabalhado part-time com crianças com deficiências através de vários programas juvenis organizados pelo o Estado Escocês, e tendo experiência na área de político social, onde dou aulas na universidade de Edimburgo nas áreas de política social e investigação social, e sendo de Portugal, esta tese é de grande interesse meu. A tese quebre se concentrar nomeadamente na Direcção Geral da Segurança Social, Família e da Criança, Instituto da Segurança Social, Secretariado Nacional da Reabilitação e Inclusão de Pessoas com Deficiências, e a Direcção Regional da Educação de Lisboa. Escolhi estes organismos pelo o facto que no report para o Comité dos Direitos da Criança da ONU, foi estipulado que as provisões do Estado para as crianças deficientes são da responsabilidade dos Ministérios da Segurança Social e da Educação. Estou a escrever-lhe para pedir permissão para fazer uma entrevista. Tendo feito entrevistas á Administração Pública, descobri que as ONGs e o sector voluntário e privado fazem grande parte do processo político-social. Anexado está a estrutura das entrevistas que tenciono fazer. Espero que esteja interessado/a em ser entrevistado/a.

Os meus melhores cumprimentos,

Sandra S. Cabrita Gulyurtlu

II. Appendix

Table 1: Distribution of Vignette responses according respondent and scale

UNIT	SELF	SELF-FAMILIAL	FAMILIAL	SELF-MICRO	FAMILIAL-MICRO	MICRO	SELF-MACRO	FAMILIAL-MACRO	MICRO-MACRO	MACRO
DGSSEFC-SA	João has Down syndrome and is on the autistic spectrum, which means he has a severe disability.	Recognises the difficulties of caring for a child or disabled person and also how difficulties can be increasingly accentuated with age. For example, changing a nappy on a child to that of a young person or an adult.	Feels empathy for the family. The parents also need holidays.	Inclusion should be practiced in schools, since children with disabilities have a lot to learn from schools and need to learn how to interact with mainstream kids, in order to prepare them for the outside	Asked if the mother's work would let her leave early and are aware of her situation. In this case, i suggest that the child's parents should place the child in a support home, during section of the holiday period, and for example collect the child on weekends. Previously these homes were	In terms of schools, inclusion is promoted This isn't reality given the governance of schools, where children can be integrated but not included. Mainly it is Institutions of Solidarity associated	The Media offer little information on disability, only once in a while there a study or documentary on a particular individual.	I feel that you cannot ask more of the families. For them to do what they want, they need support of the State, to help them deal with this situation.	The section for Social Action supports transport services for persons with disabilities. Since the State does not have the resources to directly offer these services, it supports IPSS (Private Institutions of Social Security) that offer these services.	The State has practically no established institution for social action.

				<p>world.</p> <p>Unfortunately, there isn't enough spaces within these services for everyone. One alternative is to enroll her child in a ATL, (extra curricular activity), aside from providing extra curricular activities, and these programs usually provide a service which would collect and bring João to school</p>	<p>solely the responsibility of Social Security, but now they have recognized importance of involving the Ministry of Education. In fact, the responsibility of these homes was allocated to the Ministry of Education</p> <p>At 10, João can benefit from mobile support (ambulatory regime), where specialized teams will go to ones house, evaluate ones necessities and develop the appropriate orientation and intervention for the family and child.</p>	<p>with the Church, that end up being the Institutions that are responsible for support for persons with disabilities.</p>			<p>This is due to the State being more inclined towards the objective of collaborating with Institutions of Social Security. The State gives a great amount of support to these Institutions, for example, it supports more than 4000 Institutions, not only in terms of equipment and functionality, but also in terms of financing the collective partnership of the use of equipment.</p>	
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				<p>and take care of him while his mum is at work.</p> <p>Persons with disabilities or with children with disabilities can go to their local ISS, (Institution of Social Security), or to certain IPSSs, to inform themselves of exemptions , services they have a right to, or for an evaluation of their case.</p>							
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DGSSFC-IR	People with Down syndrome are very affectionate.	<p>Felt sorry for the situation in itself and the difficulties João's mother was confronted with.</p> <p>People with Down syndrome are very affectionate, and for this reason need a caring, family network, which is social and stable.</p>	João's mother must also be preoccupied about getting old and one day not having the ability to care for him properly.		<p>She should be able to usufruct from the support of a support worker, that would help her care for João, and that would be able to support him to join extracurricular activities.</p> <p>Even if these institutions are far, having a support worker allows the mum to stay longer at work.</p>	<p>The respondent knows that it is hard to find institutions that have the right support for extracurricular activities.</p> <p>There should also be more Institutions for Respite care, in order to allow the mother short periods of relaxation and to unwind, hence replacing the school in holiday periods.</p>		João's other should benefit from a flexible work timetable, (working less hours), so that she can have a better consolidation her professional and family responsibilities.	There is also a gap in the system, which is the lack of residential institutions and other means by which to support adult persons with disabilities	As I work in the social security sector, the sadness is greater in knowing that the system does not have a response for these situations.
DGSSFC-	In relation to the vignette,	This is what I feel relative to		In this concrete		I believe a special	Now, what I would	I would suggest in this situation,	Nowadays, there is a	Now, it is also true

R	<p>this is a story that we perceive as quite common, not with the exact same characteristics as this one, but the fact is that there are situations where children with whatever may be the disability that is affecting them and being of schooling age, to have such difficulties.</p> <p>So, these situations, are quite frequent situations.</p>	<p>this situation, and is that seems to me to have to say that the issues that are here, and how the story and the characters are portrayed, it is obvious that not only João needs support, but also his mother who is the next of kin.</p> <p>She will feel the lack of means to give her own child the eventual she would like to give, in addition to that of what he receives through special schooling.</p>		<p>case, this child's situation is that he already has specific support, in the sense that he already goes to school.</p> <p>On a downwards slope from integrated education, you (the interviewer) must have spoken to someone who already spoke to a specialist of special education. In this perspective we can say that João already</p>		<p>school, which does not generally happen, since it is increasingly more frequent that these children are integrated in mainstream schools with specific educational supports.</p>	<p>suggest doing in this situation, it is obvious that, whilst just taking this situation outlined in the vignette into account and that this child already benefits of the specific subsidies that are attributed in this situation, in the perspective of my field I work in, we eventually wouldn't have anything more to give to this young</p>	<p>it is obvious that if we could offer his mother the conditions for her to be able to take care of her child, without harming her professional life, would be ideal.</p>	<p>series of situations that require specific aids of this nature and therefore, without disputing the seriousness of this situation, the fact is that the conception of disability is a broad concept, meaning that it is a concept that according to the law is more generic and therefore covers a range of very extensive situations and by covering a range of very extensive situations, we will always have the problem of whatever the social response that</p>	<p>that, from the social security regimes perspective and that is the regime I'm talking about, the responses are not treated from a personalized perspective, as they are in the area of social action that potentially has a more personalized treatment.</p> <p>But, also the fact is that those provisions are costly and at this moment we have the problem of financial sustainabilit</p>
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				<p>has, already benefits from specific support in this area, although you could argue that these specific aids can be manifestly considered to be insufficient for the child's needs.</p>		<p>person.</p> <p>One thing is that which I currently know that there does not exist anymore provisions available than that the child already usufructs, another thing is that the provision could potentially not be sufficient.</p> <p>From the perspective of social security regimes, the framework is done at the level of</p>		<p>one wants to give, it always is too expensive.</p>	<p>y of the system, isn't it?</p>
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							citizen's rights. Hence, the rights that are granted in general and abstract terms, are granted to citizens, in this case children who fulfill the conditions that specifically outlined in the law.			
DGIDC		No. In relation to the mother and child, no.	It is a very common story, and happens to many families in Portugal, just as many European countries, even today. I have the normal feelings, and the problems are the normal			For example, having no vacancies in schools, is a scenario that is not encountered in Portugal. All the schools with		So, the proceedings are so many that the mother has to go to so many different places to help solve her problems, that for a person that works it is virtually impossible.	Now, this delineates that we still have organized services, not in terms of care, or rather that the services are not directed at the citizen, because all the issues that are outlined here can be	

			problems for people who work and have children who have disabilities.			special schooling have vacancies to be filled. It isn't by chance that the English have put forward their last paper, 'Every child matters.' It is for the exact reason of, within the same service, the possibility of compiling and developing the complete set of provisions people are entitled to.			resolved by the system if there were services that assist in supplying the answers. However to receive provisions either from education or social security, they are not orientated at helping families in this area. This is the first step, services orientated at the citizen, helping the answers as quickly as possible, avoiding an immense compilation of provisions, going from	
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									service to service, looking for answers for non-integration, non-coherence between services and its lack of links and what gives rise to what we see in situations today with the existing benefits, that if they functioned properly, it would be avoidable.	
SNRIPD	What would I suggest?...		This is in generic terms and relatively in more intimate terms, as I can imagine how the mother must be feeling, to at the end of the		Implies more money than that which they are investing, with all of this and also has to miss work, reduce work hours. Or, have to resort to maybe to go on public			So, in generic terms, unfortunately this is a sad story, for all the collection of circumstances where this family, not so much the fact that... Joao has		But what was important is in fact if we created situations to not worsen the consequences of a child being born

			<p>day be handling all this surrounding her, isn't it.</p> <p>The fact of having these conditions there is always there last resource, or the last that many a time starts by being the first, is for the child to go to a full-board school, separate from the mother in a regime perfectly in a school, in a school because in fact the community cannot give her these things</p>		<p>transportation from here to there, it is not possible to be in determined place in school.</p>			<p>Down syndrome, which is obvious that it is a complex situation, and should be complex and difficult to manage. and the lack of support and conditions that are provided to, whether it is to the mother or to the child, according to their needs.</p>	<p>with whether it'd be downs syndrome or any other thing.</p> <p>It is therefore here the suggestions, it was in fact at the level of the appropriate entities that make decisions which seriously look at these problems and in fact put different policies and forms of policies into perspective, without implicating more costs than that of what has been done in a combined</p>
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										analysis. Here is an issue in specific terms of this concrete situation. Another thing is what I would suggest in organisational terms, in terms of the services and the community and the existing policies at different levels, isn't it.
DREL	When he is disabled the situation completely deconstructs, and becomes a lot more hard to handle.		It is clear the desperation of this mother, that is alone and has to assume, for example, the role of mother and father of a disabled child,			Me here, as I am within this problematic. Although currently I am in the Directorate , I have in		From there understanding the despair of this mother, which certainly isn't easy to find someone, in terms of structure is hard to find, and to go		Of course these situations are situations that I know from within. And it is realities like these, we

	<p>When the child is disabled, it is something that they can't just stay with anyone.</p> <p>So. The normal child can stay with a neighbour, a nanny, a grandmother, somebody who would care for them, a disabled child is very hard to find someone to take care of them. This has to do with the specificities and necessities of the child.</p> <p>In this case Downs syndrome and the association</p>		<p>it isn't easy.</p> <p>Therefore, I know this despair, what this becomes, therefore, if the child is normal it is already complicated for a single mother, isn't it?</p> <p>There is the issue of holidays, end of the day, and the worrying issue of who takes care of him.</p> <p>But even then, the jobs, the person leaves 5/6 hours, later the transport to get home, isn't it, sometimes takes 1 or 2 hours, and therefore you end up</p>			<p>terms of my cv, I have always been directly involved. Consequently, I am a psychologist, a teacher, so I have worked directly in this.</p>		to.	<p>could say there is realities far worse than this one here.</p> <p>What I think is that at this moment, the Government and the Ministry of Education, with the changes they have introduced , and the extensions in terms of timetabling, is attentive to this situation.</p> <p>This worries me, because I didn't always know what to say, and how to solve and help these</p>
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	<p>with the autistic spectrum makes things more complicated.</p> <p>So, downs syndrome is a child, that are in a certain way easy, in terms of a child in the autistic spectrum, no.</p> <p>It is an extremely difficult relationship, therefore, autism comes there is a problem in communicating.</p>		<p>appearing always at the end of the day or the beginning of the morning, this is the necessity for having someone to care for your child for you.</p> <p>As a result, there is a need for a support network, these families need a support network. A neighbour, a nanny, a family member, this is not always easy.</p>							families in these situations.
ISS-D	In this case, Joao can, its real, and therefore	Normally, here even adds more depth to the caring	Yes, the feeling that come out with this story, is		Full board, the parents, in the despair in inverted	It also isn't a solution that exists that often,		They want a solution to this problem. They want to work,	From start if people had this possibility,	we also have to highlight here that

	<p>these other scenarios are even more serious than the situation here.</p> <p>Exactly, the issue of disability is a transversal are.</p>	<p>relationship that exists between Joao and the mother, because what normally happens and from my experience at work with this type of family, sometimes the families already for...</p> <p>If there is some form of rejection to the issue of acceptance of Joao's disability of the family or not.</p>	<p>really the illustration of many of the situations that are lived by these families that have a disabled child.</p> <p>Already don't question the fact that they cannot stay with their child during the week, like propositioned here to Joao's mum, isn't it?</p> <p>Because he cannot stay without support, or rather the perception I have is that many of the families are already in such a state that they would go and grab any opportunity that the school,</p>		<p>commas, having to work and not having where to leave their child, is stronger than many times the need for affection, the need to be with their children during the week.</p> <p>Although obviously that this does not invalidate the feelings that these families have, that it can't be like this mother who wanted the ideal, which is having the support that would allow her to be with her child when she comes home at night.</p> <p>This family, that this mother,</p>	<p>also there is a major necessity for places in residential homes and homes for children and youths.</p>		<p>sustain the household, and not having their child at home alone.</p> <p>Or rather, the solution that the answer that is found, isn't in accordance with the family's needs, and in this perspective that would be seen, obviously if it were in the social security field it had to be seen, another response would have to be found that met the needs of this family.</p> <p>And that would happen by mobilizing a combination of resources, as ISS-C was mentioning the issue about a formal or</p>	<p>better for us, but it still wouldn't be the solution. It's the solution for some situations but not a possibility for all.</p> <p>Exactly, and this ties in with the logic of that which is of some services and some responses that social security develops and comes from the IPSSs that have established Cooperation Agreements with social security in order to develop a combination of predestined responses,</p>	<p>Joao is 10, or rather he has the obligatory schooling age, and from a simplistic perspective, if you can put it in those terms, the competency that is responsible of Joao's support is within the area of education.</p> <p>There isn't a single Ministry, no organism that retains all the competencies relative to this area, and this is because in a person's life cycle, one</p>
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			<p>the school proposes for her son to have full board, without a shadow of a doubt the majority of families would say, if that is possible then better for us. One less problem, isn't it.</p> <p>Or be it this is a case that there is no concrete answer. It has to be analysed in relation to the real necessities of this family's case and other latent necessities.</p> <p>Here, also would be good to explore, with the rest of</p>		<p>isn't it, with her son, this situation once that the school has given what it had to offer, doesn't fulfill the necessities of this family or be it, covers a part of the necessities of Joao's support is being supported in the period she is working, but in addition, the needs that this family also that Joao feels strongly about being with his mother at the end of the day isn't fulfilled.</p> <p>The reality, the reality would be Joao having support while his mother is working, isn't it?</p>			<p>informal network at the resources level, that this particular family can have here, initially could not have thought that that would be the solution, but for this issue that would also be a form, one of the fields to explore with this mother.</p> <p>This appears to be solved from the beginning of the issue, which wasn't necessary to activate another means or provision that this, yes, could also be part of social security, to the extent of supporting the family in the sense of integrating him in some type of home for him to</p>	<p>whether it be with disabled people or children with disabilities that also can take advantage of these responses.</p> <p>And the question in this logic, as I was saying the suggestion of intervention, which always comes as an integrated approach or be it a integrated intervention in this perspective.</p> <p>But also the articulation that social security, in this case, would have, in this case,</p>	<p>can be born with a disability, have a baby which later has to be born with problems and is diagnosed with a disability and the support plan will be from birth to the terminus of their life, but at any time we are here so called normal in inverted commas, as I usually say at any time we can be in a situation of disability.</p>
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			<p>the family, questioning until what point is this isolation of these two people, because of natural circumstances of life, they are alone or try to understand if there is some distancing from the closest relatives side, may it be uncles and aunts, grandparents.</p> <p>Furthermore, understanding if accepted or not, and understanding a bit the dynamics of the family, also understanding if they could understand the</p>		<p>She herself cannot solve the situation and has to articulate with others, services that also have competencies in this area, in order to find an adequate solution for this family.</p>			<p>stay the night. Or rather, the need, isn't it? seems to me, that its being forced for the fact of a lack of response in the system of education.</p> <p>For me it doesn't make it viable, that the school organises a specific program for Joao, because if he is a youth a child with down syndrome and also has autism, he needs specialised support and obviously needs to develop a combination of competencies, even if it isn't at curricular level or his his academic path, may they be competencies of social networks so that</p>	<p>with other sectors of the public administration , if not, from a IPSS of the city hall, as ISS-C mentioned some team that could essentially articulate a combination of answers with other sectors to find a more appropriate response to these needs.</p> <p>The idea that we were talking about did not transpire, of a more integrated intervention.</p> <p>Initially, isn't it, in this component of extracurricular</p>	
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			<p>natural resources that they have and still can have.</p> <p>To work in terms of if not, if there is a distancing of the family as a result of not accepting Joao, I am putting forward the option or from another type of, other factor that has caused this rupture and also can be worked on with this family, in a way, retie some family ties.</p> <p>That they promote or be it capacitate this family for it can solve this situation, and not stay</p>					<p>they can promote social integration and who knows one day professional, obviously has to have wit the development of an useful activity. He feels good developing.</p>	<p>activities or be it education has the tools to work with children with special needs.</p> <p>And in a way, services are organised in a way that, in terms of their support competencies have offered, due to the people that find themselves in that situation, always also in terms of social cultural and professional integration and in accordance with its capacities, here it seems to me that this issue of the post-school</p>	
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			waiting for a response from the school in this case, isn't it?						period and post extracurricular activities, if the school managed, in the appropriate organisms, for the Ministry of Education to integrate this child in one of the responses they develop, so that Joao can stay until the time his mum can pick him up.	
ISS-C	On the other hand, it also doesn't transpire here that he also had an previous intervention. Or rather all that has to do with the mother.	So, the idea that in fact this mother is very isolated and alone in terms of the framework of her child.	Me, one of the feelings that arises from this story, or from this story really, is the isolation which it seems the mother has. Or rather, it only mentions the mother, so it is	But on the other hand, the school that he goes to, is a special school, it also appears to not respond to the needs of the	There doesn't seem to be any support network whether formal or informal, so not at family level or services level. All that support network, therefore in social security,	Or rather, the special school that does not offer extracurricular activities during the holidays, does not assure the framework	This child could perfectly be placed in a framework that allows him to maintain his natural mother.	One of the first preoccupations of intervention, is in fact the breaking of the isolation of families. Here it shows, also the need for support, to the mother herself, also to parents of	In the area of the education system, where there is in fact adequate programs and measures for these age groups, and will always be in this integrated perspective,	Well, the feeling in fact, in my opinion shows many situations that we encounter in our day-to-day. That it is in fact this

			<p>a mono-parental family.</p> <p>And in fact, in the situations involving disabilities and harmful situations that affect children, this is in fact constant.</p> <p>Therefore, the isolation in which these families are, is therefore a bit like the second query.</p>	<p>children that attend it.</p>	<p>these subsidies that she has that gives nappies and all that is there, but in terms of the social security support network, the city hall, in terms of transport, all of that does not transpire here, so the idea is in fact that she is isolated.</p>	<p>needed for the children.</p> <p>Even more so, the school could also work as a motor of support, all this does not transpire here.</p> <p>Therefore, the idea that this school, although it is a special school, it closes in on itself.</p> <p>Isn't it here that school could perfectly be the motor of a support network, isn't it?</p>		<p>children with disabilities, which is an issue as well, that is very important and therefore also tackling this issue of isolation that is many a time a difficulty of the remaining family. Hence of the situations.</p>	<p>where disability has to be confronted as a social risk, let's say that is inclusion.</p>	<p>difficulty of framing these situations.</p> <p>In this case the child has disabilities, but there are situations, even in terms of social risk or situations that can be harmful, that pass through here too. Isn't it?</p> <p>This difficulty in response activation and the necessary resources or responding to the necessities of the child.</p> <p>It is a major discourse even from</p>
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										<p>the State.</p> <p>Early childhood intervention, here, also doesn't transpire, because if there was this intervention, Joao would be in a different framework. Therefore it is also another fault which eventually we can refer to.</p>
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